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SETTING A FEDERAL AGENDA FOR ALZHEIMER'S DISEASE

HEARING

BEFORE THE

SELECT COMMITTEE ON AGING
HOUSE OF REPRESENTATIVES

NINETY-NINTH CONGRESS

SECOND SESSION

APRIL 11, 1986, DETROIT, MI

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CONTENTS

OPENING STATEMENTS

Page

Richard Douglass, Ph.D., Department of Family Medicine, Wayne State University School of Medicine 1
Henry Nadler, M.D., dean, School of Medicine, Wayne State University 2
Elizabeth Richards, representative for Gov. James J. Blanchard of Michigan ... 3

MEMBERS' STATEMENTS

Geo. W. Crockett, Jr 4
Edward R. Roybal, chairman of the committee 4
Dennis M. Hertel 17
John Conyers, Jr 27

CHRONOLOGICAL LIST OF WITNESSES

Carol Jones, caregiver, Lansing, MI 8
Nancy E. Lombardo, Ph.D., chair, chapter committee, national board of directors, Alzheimer's Disease & Related Disorders Association, Bloomfield Hills, MI 12
Fred Pankow, Michigan State Legislative Committee, American Association of Retired Persons 17
Susan Rourke, executive director, Citizens for Better Care 29
Gloria Smith, director, Michigan Department of Public Health 40
Dr. Zaven Khachaturian, Chief, Physiology of Aging Branch, National Institute on Aging 46
Tom Crook, president, Memory Assessment Clinic 56
David Hollister, chairman, Appropriations Subcommittee on Social Services, Michigan State Legislature 60

AUDIENCE PARTICIPANTS

Helen Dent, Flint, MI 67
Harvey Altman, Department of Psychiatry, Wayne State School of Medicine ... 68
Thelma Medrea, Mount Clemens, MI 70
Joseph Hess, chairman, Department of Family Medicine, Wayne State University of Medicine 71
Elmer Benson, Detroit, MI 76
Sid Gilman, chairman, Department of Neurology, University of Michigan in Ann Arbor 78
Dr. Roger Morrell, Chief of Neurology, VA Medical Center, Allen Park, MI 81
Greg Lundsted 82
Henry Wisniewski, director, Research Institute in New York 83
Diane Wilkins, executive director, Alzheimer's Disease and Related Disorders Association, Detroit area chapter 83
Jim Erickson, Mid-Michigan Chapter of ADRDA 84
Sharon Balasco, Flint, MI 85

APPENDIX

Additional material submitted for the record: "Public Policy Recommendations," by Jim Strong, Oakland, CA 87
Statements of:
American Association of Homes for the Aging 104

Statements of—Continued Page
Sharon Balasko 110
Robert W. Bowman, Ann Arbor, MI 112
Barbara J. Brink, member-at-large, board of directors, Allegan-Ottawa [ADRDA], Holland, MI 113
Lenore K. Frontczak, Detroit chapter Alzheimer's and Related Disorders Association 114
Debirah A. Gerbasi, Detroit, MI 115
Clare Brown Lyle, Mount Pleasant, MI 117
Roger M. Morrell, MD., Ph.D., Lathrup Village, MI 119
Dorothy A. Nini, Dearborn, MI 120
Dorothy M. Parker, Redford, MI 121
John E. Rex, ADRDA, Midland, MI 122
Frieda Schneider, Marne, MI 123
Mary Ruth Seman, Saginaw, MI 124
Dorothy E. Booth, Ph.D., R.N., assistant professor of Nursing, Wayne State University, Detroit, MI 125
Bernice Crampton, Saginaw, MI 126
Patty Close, Hemlock, MI 127
Roy W. Haggberg, Marysville, MI 128
Jane K. Hillman, Saginaw, MI 129
Minnie Kipp, Saginaw, MI 130
Elizabeth G. Murray, Plymouth, MI 131

SETTING A FEDERAL AGENDA FOR ALZHEIMER'S DISEASE

FRIDAY, APRIL 11, 1986

HOUSE OF REPRESENTATIVES,
SELECT COMMITTEE ON AGING,
Detroit, MI.

The select committee met, pursuant to notice, at 9:30 a.m., in the McGregor Memorial Conference Center, Wayne State University, Detroit, MI, Hon. George Crockett, Jr. (acting chairman of the committee) presiding.

Members present: Representatives Crockett, Hertel, and Conyers.

Staff present: Gary Christopherson, professional staff member, Select Committee on Aging.

STATEMENT OF RICHARD DOUGLASS, PH.D., DEPARTMENT OF FAMILY MEDICINE, WAYNE STATE UNIVERSITY SCHOOL OF MEDICINE

Mr. DOUGLASS. Ladies and gentlemen, I'm Richard Douglass, a member of the faculty of the Wayne State University School of Medicine, and a member of the program and planning committee for this national conference on Alzheimer's disease.

On behalf of the program and planning committee, I'm first of all, delighted that you are all here. And I am privileged to offer an enthusiastic welcome to the Select Committee on Aging of the U.S. House of Representatives. We are delighted that this committee is holding this field hearing here in Detroit, on one of the most difficult health and social issues facing the Nation's elderly and their families.

The essential issue of today's hearing is to suggest directions for legislative initiatives by the Federal Government, and to voice support of legislative leadership by the Select Committee on Aging in the area of Alzheimer's disease and related disorders.

We are all hopeful that legislative initiatives comparable to the comprehensive Alzheimer's Disease Assistance, Research and Education Act will soon be enacted into law. And furthermore, that such legislation will be fully appropriated as a crucial first step toward achieving parity with other comparable causes of mortality and morbidity. In terms of Federal assistance and direct support, there is no alternative to this course of action.

I hope that this hearing informs the Congress, challenges the Select Committee on Aging, and stimulates the entire Federal Government to focus on an agenda for Alzheimer's disease. We seek to

assist you to tackle these difficult problems with renewed energy and sense of mission.

It is an honor to be here to welcome you. Thank you for offering your time and attention to the issues being raised here this morning.

STATEMENT OF HENRY NADLER, M.D., DEAN, SCHOOL OF MEDICINE, WAYNE STATE UNIVERSITY

Dr. NADLER. I'm Henry Nadler, dean of the School of Medicine at Wayne State University. On behalf of the faculty, the students, the administration, the teachers, the clinicians, the staff, and the investigators, I'd like to offer a warm welcome to the U.S. House of Representatives Select Committee on Aging.

It is particularly gratifying that the focuses of this hearing are on one of the most important issues of the day, Alzheimer's disease. Alzheimer's disease is a large and growing problem in America. Not only is it a complicated medical condition and major cause of death, but also a frightening and expensive burden to a family and an ominously prevalent basis for long-term care.

It is now the fourth leading cause of death of adults and over 120,000 will die this year. Over 30 percent of all long-term care patients suffer from this poorly understood disease. By the year 2000, it is estimated that victims of Alzheimer's disease will exceed 3 million in the United States.

Alzheimer's disease is a significant challenge to researchers who are struggling to find answers to its causes, manifestations, and methods of treatment. Progress along these lines is difficult with inadequate and dwindling support from public and private sources.

Our professors are challenged to establish curricula which include Alzheimer's disease in the growing field of geriatric medicine. Support for this kind of activity is essential for keeping medical education current with scientific findings, is difficult to acquire, and is usually too short lived for sustaining program development.

Today, even with these inadequate levels of support for research and training, they are being threatened. There is indeed an urgent need to address the question of adequate levels of support for Alzheimer's and related diseases when we consider that medicine is in a significant state of transition. That transition is toward increased focus on health questions for the elderly.

We are a population growing older and staying alive longer. Soon, diseases of the elderly will be the diseases of the majority. I am hopeful that this hearing might serve to draw the attention of Congress and the Nation to one of the most important issues of the day. We stand ready to study, to teach, and to labor for solutions of the problems addressed in today's hearing. We will learn more, we will teach better, and we will provide for our responsibilities and hope that Congress and others will meet theirs.

I wish you great success today, and I am pleased that our school of medicine has been instrumental in bringing this hearing to Detroit.

STATEMENT OF GOVERNOR JAMES J. BLANCHARD OF MICHIGAN AS READ BY ELIZABETH RICHARDS

Ms. RICHARDS. Good morning. My name is Libby Richards and I'm the human services program specialist for Governor Blanchard.

The Governor asked that I convey his apologies and regrets that because of scheduling conflicts, he was unable at the last minute to attend the hearing, and to talk to you about not only his concerns about Alzheimer's but what we are going to be doing in our State. He asked that I attend on his behalf and I will be here for the entire morning to hear the testimony, and to convey to you his concerns through this letter, which I would like now to read.

"Congressman Crockett and members of the Select Committee on Aging, I am pleased, Congressman Crockett, that as a distinguished member of our State delegation, you will be chairing today's important hearing on Alzheimer's disease and have brought members of the select committee, including our own Congressmen, Dennis Hertel and Paul Henry, to join you.

"I am also pleased that you are holding the hearing at Wayne State University, one of Michigan's major institutions of higher education, which has been in the forefront of public policy development on the Alzheimer's issue.

"Because of my concern about the burden that Alzheimer's disease represents to our State and those families affected, I addressed the issue in my January 1986 state of the State message, directing my human services cabinet to identify the key issues surrounding Alzheimer's and other related disorders, and to formulate recommendations for our State.

"The human services cabinet has designated the department of public health as the lead agency for this effort. Later in this morning's hearing, Dr. Gloria Smith, my director of public health, will be reviewing with you the process that has been developed to carry out my request.

"I recognize that such a serious health problem as Alzheimer's must be addressed with the input, involvement, and commitment from both the private and public sectors; specifically, local communities, business, academia, health professionals, and citizen advocates, as well as State government.

"The Federal Government must play a key role in addressing this problem, particularly in continuing research on the causes and earlier identification and prevention of Alzheimer's and related diseases. The testimony presented today and the national conference being held concurrently will provide valuable insights into the complexities of this problem. I am pleased that the Select Committee on Aging has recognized this Federal responsibility, and is taking the lead through congressional work, on developing more education and resources for Alzheimer's patients and their families.

"The State of Michigan, through its task force on Alzheimer's and related diseases, will be developing recommendations which I will be pleased to share with you.

"Again, thank you for coming to Michigan, for inviting us to join you today, and for addressing this important issue."

And as the Governor's human services specialist, I might just mention that I work very closely with the cabinet, which is composed

of the directors of social services, mental health, education, public health, the office of services to the aging, and the office of substance abuse issues. They are all very concerned about this problem, and through the work of the task force, I will be very involved in helping to get those recommendations ready for the Governor.

I will be in attendance through the rest of the morning, and I am delighted to have this opportunity to join you today.

Thank you, Congressman Crockett.

STATEMENT OF REPRESENTATIVE GEO. W. CROCKETT, JR.

Mr. CROCKETT. The House Select Committee on Aging will come to order. And I'm sure it's a matter of some surprise to many of you that a whole congressional committee is represented by just one Representative.

Believe me, this is one of the peculiarities I've come to expect, as far as the operation of the Government is concerned. I'm hopeful, however, that we will be joined later by two other Congressmen from the State of Michigan and they will be introduced at that time.

I am George Crockett, Congressman from the 13th Congressional District. The 13th Congressional District embraces all of the inner city of Detroit, and includes Grosse Pointe and Grosse Pointe Park.

The House Select Committee on Aging is chaired by the Honorable Edward Roybal, from Los Angeles. Unfortunately, Chairman Roybal is unable to be with us and he has designated me to preside.

I will later share with you some views that he would have presented, had he been able to be here.

I want to express appreciation for the warm welcome that we have received from the faculty of medicine here at Wayne State University. As a matter of fact, it's been most unusual, because ordinarily, the staff of the committee which is represented here today by Mr. Christopherson here at my left, has to do all the footwork putting these hearings together. In this case, Dr. Douglass and the members of his committee have done an excellent job of arranging for these hearings, and we are extremely grateful.

I'm directing that the comments made by the representatives of the university be included in the official record of these proceedings. The excellent statement from our Governor which was presented here was supposed to have been presented after the committee was called to order. But we will take care of that little slipup by directing that it also be included in the minutes.

Now, for the remarks from Chairman Roybal, which I said I would share with you.

STATEMENT OF REPRESENTATIVE EDWARD R. ROYBAL, CHAIRMAN, HOUSE SELECT COMMITTEE ON AGING AS READ BY REPRESENTATIVE CROCKETT

Mr. CROCKETT [reading]. "It is with deepest regret that I am unable to participate in today's most critical hearing.

"I want you to know that the fight against Alzheimer's disease and the tremendous burden it places on millions of Americans is

one to which I am deeply and personally committed. Unfortunately, it is a fight we have only just begun.

"Fortunately, the fight has many allies in the Congress. I can assure you that they and I have much in common including the commitment to the health of all Americans. Today we share another common bond—a commitment to helping the victims of Alzheimer's disease.

"How to care for the victims of Alzheimer's disease and related disorders is an important issue, just because so many people suffer from these diseases. The issue becomes even more important when you consider that the cost of their care to families and the Nation is more than $20 billion annually. Though the financial cost is great, the greatest tragedy is still the human cost for the victims and for their families.

"Congress must go beyond simply understanding this enormous tragedy and proceed to take immediate additional action. I am convinced that Alzheimer's is an exceptional disease which requires exceptional handling by the Congress this year. In 1985, we spent only $43 million on Alzheimer's related research. With the exception of Medicaid, virtually nothing is being done by the Federal Government to help the victims or their families.

"Though 1986 is known as the year of Gramm-Rudman, Alzheimer's disease clearly demands special attention. In my own bill, H.R. 2280, I am proposing a substantial step forward in funding for research, and a beginning step in support for the families. Fortunately, there are also other important pieces of Alzheimer's legislation which should be considered.

"With the help of today's hearing, we will develop a Federal agenda for Alzheimer's disease which joins together the forces of the families, the Alzheimer's Disease and Related Disorders Association, the universities, the States, and the Federal Government. With the help of all these committed people and organizations, we can and will move forward a Federal agenda that helps the Alzheimer's victims and relieves some of the tremendous burden their families carry.

"Again, I want to express my deep regret for not being able to be with you today. I greatly look forward to Mr. Crockett's return to Washington to brief me on this most important hearing. Most importantly, I look forward to enacting a significant and supportive piece of Alzheimer's legislation in this session of Congress."

That completes the statement sent to us by the chairman of the full committee.

Now, the House Select Committee on Aging is conducting this hearing to examine the difficulties faced by Alzheimer's disease victims and their families, the progress made in Alzheimer's research, and the need for further action by Congress this year.

The Select Committee on Aging has no legislative responsibility. Its responsibility essentially is one of investigating, and making recommendations to the committees that do author the legislation. Individual members, of course, may propose legislation and that is what Chairman Roybal has done in his bill. Later on, I will call attention to other bills that have been introduced in the House to address these problems.

Alzheimer's disease and related disorders cause enormous problems for the people suffering with these diseases, for the family members who care for them, and for society which desires to be supportive of Alzheimer's victims. Over 2.5 million Americans have this disease, while the total number of family members and friends affected in some way by the disease is much larger than 2.5 million.

The cost of caring for the victims is terribly high in both monetary and nonmonetary terms. The monetary impact, over $20 billion annually, is a heavy burden for Government, and most especially for the families of Alzheimer's victims.

Given this monumental tragedy, there is a great need to help support the victims and their families and to fund Alzheimer's related research on the causes and possibly a cure. Research to date has been primarily funded by the Federal Government, and has focused on finding the causes of Alzheimer's and related disorders. More and more is being learned about these diseases and about ways to help the victim and family cope with the problem.

However, even with this progress, the discovery of preventive measures or a cure will require much larger investment in research than is being made currently. In 1985, the National Institutes of Health is funding only about $43 million in Alzheimer's related research. Clearly, Alzheimer's research is severely underfunded.

The challenge for the Congress is to decide just how high a priority to place on finding the causes, the prevention, and/or the cure of Alzheimer's disease and the related disorders. Given the enormity of the burden, Congress needs to decide if Alzheimer's research should be funded at levels comparable to current cancer research funding. The current level of cancer research funding is over $1 billion. That was the amount appropriated in 1985.

Beyond the funding of research, the Congress in partnership with the victims, their families, and the States, must take steps to help the victims and their families now. Currently, Federal support is limited to those poor enough and disabled enough to be entitled to Medicaid payment for nursing home care.

Considering the urgent and immense need, there is no question that the Federal Government must do more. Congress should focus its attention on what can be done and where to find the resources to pay for it. Even in this year of tight budgets, next year is not soon enough for Congress to take the first step toward reducing the hardships of caring for America's Alzheimer's victims.

I said that I would acquaint you with what is pending in Congress. I mentioned the bill offered by Chairman Roybal. Congressman Pepper has introduced the Alzheimer's Disease and Related Disorders Treatment Act of 1985. This bill calls for the establishment and the funding of 20 centers, nationwide, to treat people with Alzheimer's disease.

This bill, H.R. 524, has garnered the support already of 140 cosigners in the House.

Congressman Michael Bilirakis, from Florida, has introduced H.R. 66 and H.R. 67, which promote support groups for families of victims of Alzheimer's disease and which provide for Medicare

demonstration projects experimentally providing Medicare payment for Alzheimer's disease victims, respectively.

Now, while there has as yet been no hearings held on any of these bills by the committees to which they were referred, it is hoped that the publicity and the pressure generated by hearings and conferences such as we are having here today will help get one or more of these important bills passed.

And as will become clearer as our witnesses speak, such Federal legislation is very much needed.

I want to close by thanking the department of psychiatry at Wayne State University, the Detroit Area Chapter of the Alzheimer's Disease and Related Disorders Association, and the Levine Institute on Aging for their help with this hearing, and for sponsoring and organizing the National Conference on Alzheimer's Disease and Related Disorders which is taking place now.

Our first witness will be a panel of three people. That panel includes Mrs. Carol Jones, Dr. Nancy Lombardo, and Mr. Fred Pankow.

Ms. Jones has been caring for her mother, who is a victim of Alzheimer's disease, for the past 12 years and will share with us what that experience has meant to her and to her family.

Dr. Lombardo is a member of the board of directors of the National Alzheimer's Disease and Related Disorders Association, and founder of the Detroit area chapter of ADRDA, and speaks from the personal experience of having a mother who has suffered from Alzheimer's disease for 20 years.

Mr. Pankow represents the Michigan State Legislative Committee of the American Association of Retired Persons, which is probably the largest organization representing older people in the world.

Following that panel, we will have a panel consisting of five people. Those five include Susan Rourke who is the executive director of Citizens for Better Care, a 17-year-old statewide consumer agency group trying to protect and improve the quality of care offered in Michigan's nursing homes and adult foster care homes and other long-term care centers. She will discuss how Alzheimer's disease patients' symptoms affect the kind of care they get.

Then we will have State Representative David Hollister, who is chairman of the State House Appropriations Subcommittee on Social Services, the subcommittee that has jurisdiction over the Michigan programs that do or could provide assistance for Alzheimer's disease patients and their families.

And State Representative Hollister will be followed by Dr. Gloria Smith, who is the director of the Michigan Department of Public Health. She will discuss the newly formed Michigan State Task Force on Alzheimer's Disease and Related Conditions and what it hopes to accomplish.

Now, after our two witnesses discuss State of Michigan activities, Dr. Zaven Khachaturian, who is the Chief of the Physiology of Aging Branch of the National Institute on Aging will discuss what is happening on the Federal level in terms of research into the causes and treatment of Alzheimer's disease.

And our final panel will include testimony by Dr. Thomas Crook, who is currently the president of Memory Assessment Clinic, Inc.,

in Maryland and who is a former director of the National Institute of Mental Health program in developing effective treatment for Alzheimer's disease.

I extend the committee's welcome to each of these witnesses. Your statements, insofar as they've been filed with the committee, will be made a part of the record, and you will proceed as you like. We are somewhat pressed for time, so to the extent that you can summarize your statement, that would be very much appreciated.

Now, the first witness, I take it, is Ms. Carol Jones. Welcome, Ms. Jones, you may proceed.

STATEMENT OF CAROL JONES, CAREGIVER, DAUGHTER OF ALZHEIMER'S VICTIM, LANSING, MI

Ms. JONES. Good morning, Mr. Crockett. My name is Carol Jones, and I'm a family caregiver who is most appreciative of this opportunity of telling you of my experiences, needs, and desires.

My mother has just turned 68 on her birthday this past Tuesday, and has been a victim of Alzheimer's disease for perhaps the last 12 years. I'm speaking to you today of Alzheimer's disease and related disorders but my comments will refer to same collectively as simply, Alzheimer's.

In 1974, my mother, 56, began displaying noticeable memory loss and occasional disorientation problems which were initially diagnosed as stress-related. At that time, this was an understandable explanation as she was an active high school mathematics and English teacher within the Detroit public school system. Further, she had just completed some course work for her doctorate level degree in education.

However, as time passed, her personality, in fact, all of her behavior, gradually became increasingly uncharacteristic: unpredictable, unsociable, sometimes volatile, and generally upsetting, especially to my stepfather who was also attempting to care for the daily needs of his own elderly homebound parents. Ultimately, my mother's behavior became as confusing as it was confused. She became regularly explosive, abusive, and paranoid in nature. In 1979, she was forced to retire early from her teaching, the diagnosis then being arteriosclerosis or premature hardening of the arteries. Though a disability retirement was sought, this was repeatedly denied by the Social Security Administration, as mother was determined to be, among other things, still able to work and not homebound.

During 1980, mother actually stopped bathing herself, cooking, reading, and singing in the church choir. Her home became a jumble of old newspapers, discarded clothing, dirty dishes and a haven for secretly hidden money, utility and other bills. To even touch or discuss her environment meant instant outbursts of uncontrollable anger and sometimes physical combativeness. This situation completely drained and unhinged my stepfather's vitality, leaving him an uncontrolled hypertensive diabetic with angina pectoris complications. It was shortly after my mother became confused one afternoon during the winter of 1980, hopped a bus to visit her sisters in Baltimore, MD, and got lost for 17 hours in Pitts-

burgh, that I decided that despite her most vehement objections, that her place was best within my Lansing, MI, home.

My stepfather's best intentions had to also take a back seat to the realities of his own stress and declining health.

Beginning in 1981, as mother turned 63, we canvassed various community agencies and services within and around the Geater Lansing area. I was looking for an activity in which mother could participate so she would not be completely alone while I worked. Unfortunately, we were not generally eligible for services, either because of my mother's need for constant supervision, or because of her unpredictably argumentative and sometimes volatile behavior, or because our two-member household and even she, alone, earned more than the allowable financial guidelines, or because my mother was living with me, and not actually alone in her own home.

The bottom line, either my mother with her $12,000 annual income made too much money to qualify for various programs, or her condition precluded her from any participation.

During 1981 and 1982, my mother was generally still able to remain at home alone during the day with the assistance of no less than eight or nine phone calls from me, and with the assistance of my neighbors, particularly one teenager I hired to provide after school companionship.

During 1983, I had to increase this pattern of supervision by altering my working schedule to accommodate trips home to prepare lunches. However, when my mother's behavior, confusion, and general health became more erratic, especially during April 1984, I finally began to administer a prescribed sedation to curb the midnight wanderings, the physically combative confrontations, the difficulties in accomplishing grooming and dressing, and to generally make her more receptive to and acceptable by area home health agency services.

By this time, mother had just been diagnosed as being an Alzheimer's disease victim, though confirmation of this is not really possible until after her death. Also, by this time, I was diagnosed as a basket case. My work was affected and I suffered from sleep deprivation. When I did sleep, I ground my teeth to the point of requiring extensive dental surgery. But most frightening for me was a period of uncontrolled weight loss until I weighed only 93 pounds.

In September 1984, my mother simply was not able to swallow her food and she was hospitalized after collapsing in my arms. After only 4 days, she was released home to me. For weeks she remained in a sleeping fetal position. She had to be turned every 2 hours and tube-fed every 6 hours.

Her arms and legs had to be exercised, her catheter emptied periodically and her urine output monitored. By Thanksgiving, thanks to the fantastic help of a live-in aide, mother was able to get out of her bed and wheelchair and able to walk again. She was also finally able to resume eating her meals, although these are still specially prepared for her and still supplemented.

It was at Christmas that mother told me, I love you. This was her longest sentence in months. Today, mom is rarely sedated, the so-called difficult behaviors have passed. She's frail but she's generally healthy, she enjoys and benefits from her day care center

visits and she readily responds to hugs, kisses, and the purring of her kitty cat.

But mom can't feed herself; she can't even blow her nose. She has to be bathed and dressed; she can't control her bladder, and her vocabularly consists of only a few single words she rarely utters anymore.

During 1984, from just May through December, almost $6,000 or 48 percent of my mother's $12,500 retirement income, was spent on private duty and agency health aide services, feeding tubes and bags, formulas, diapers, special bedding, floatation, lambs wool and gel pads, restraint belts, wheelchair and hospital bed fees, commode and safety belt equipment, all not covered by either Medicare nor my mother's supplemental health insurance policy.

In addition to these expenses, I used my own income to insulate and then install a lavatory facility in my basement to house live-in assistants in an effort to trim the $275 per week cost of agency nursing services. The major part of this needed modification of my home was also not reimbursable by Medicare or private insurance, nor was this expense deductible on my Federal, State, or city tax filings.

During 1985, a little over $10,300, or 78 percent of my mother's $13,200 retirement income, was expended for private duty home care, day care center costs, special liquid dietary supplements, diapers and the excess rental for hospital bed. So far in 1986, the home health aide costs alone have equaled 100 percent of my mother's monthly income of $1,090. All of the other expenses have been out of my pocket.

One of the hazards of choosing to be a public school educator instead of striving early to amass millions, is that a teacher's accumulated savings are quickly depleted by Alzheimer's disease. These past 2 years especially have done much to eliminate my mother's nest egg. Its end is in sight. However, the main alternative to paying for almost everything out of pocket, is the relocation of my mother into a nursing home, followed by the final liquidation and then use or assignment of her assets and income to cover the $18,000 to $25,000 per year nursing facility cost, thus securing her qualification under the State's Medicaid Program.

I point out here that the nursing home's custodial care is also not covered by either Medicare or private health insurance.

This Medicaid dependent nursing home option is rather drastic when one considers that my mother was always an active career woman and traveler, the holder of advanced educational degrees, a social worker, mathematician and devoted educator who never once dreamed that her thrift, prudence, and best laid plans, as well, as her talents, vitality, and even basic memories would disappear with her financial independence, because of the ravages of Alzheimer's disease.

I have a wish list.

I'm a caregiver and wish my mother didn't have Alzheimer's disease.

I wish there was greater meaningful attention paid to Alzheimer's by the public, the professional provider, and our Government.

I wish there was more research into this disease's cause, cure, and at least, treatment.

I wish we could develop better diagnostic procedures and tools because so much suffering happened in my family, as in others, as a result of not being able to properly identify this disease earlier.

I wish more professional health care providers, especially physicians and nurses, were trained and knowledgeable in the unique and difficult aspects of providing care for the Alzheimer's disease patient, which includes the recognition and servicing of the needs of the family and caregiver.

I wish there were day care, respite care, and affordable long-term care housing options available in every city and county across this country, with staff specially trained in the care and management of Alzheimer's victims.

I wish age restrictions were invisible in terms of Alzheimer's victims eligibility for services and care.

I wish Medicare and private insurance companies would provide coverage, even if optional, for the so-called custodial care needs of the Alzheimer's victim, as well as respite and supporting services for the caregiver.

I wish the Social Security Administration would appropriately recognize Alzheimer's disease as a truly disabling affliction, even if the diagnosis is made after retirement has begun because of this affliction.

I wish caregivers and families were permitted a tax credit and deduction on their annual tax return as an encouragement to their efforts of providing care in the face of almost assured Medicaid and other governmental dependence.

I finally wish that each of you here today could hear the words of my fellow caregivers who have related to me their experiences dealing with the inconsistent policies of the Veterans' Administration regarding the eligibility, care and treatment of their spouses.

Finally, with my wishes, I have one listed hope and one dreaded fear.

I hope I never suffer from Alzheimer's and its devastation and its totality.

But I greatly fear that this disease of the century will march with us into the next century if we don't act now to address its presence and consequences.

Thank you for allowing me to speak with you today. Again, I'm most appreciative of this opportunity.

Mr. CROCKETT. Thank you, very much.

Ms. JONES. I would also like to add that Congressman Conyers knows my mother and he would not recognize her today.

Mr. CROCKETT. Thank you for your personalized statement of what you have gone through, as so many others are going through now, and the necessity that Congress take some action.

We have been joined by the Congressman from the First Congressional District in Michigan, my colleague, Congressman Conyers, who is the ranking member of our Michigan delegation in the House. Congressman Conyers is concluding his 11th term as a Representative from the northern and far western part of the city of Detroit, and the city of Highland Park.

Awfully glad to have you with us, John. Do you have some introductory remarks?

Mr. CONYERS. No, Mr. Chairman. Good morning. I want to commend you for having the foresight to call a hearing specifically around a disease that's an increasing problem in our community. I want to join with your efforts of the Select Committee on Aging, in trying to bring some of the wish list into some reality. And that's going to be a congressional, a political, and a legislative responsibility that I suppose we'll have to repair, after this hearing.

Mr. CROCKETT. Thank you, very much.

Our next witness is Ms. Nancy Lombardo who is a member of the board of directors of Alzheimer's Disease Related Disorders Association.

Welcome, Ms. Lombardo. You may proceed.

STATEMENT OF NANCY E. LOMBARDO, PH.D., CHAIR, CHAPTER COMMITTEE, NATIONAL BOARD OF DIRECTORS, ALZHEIMER'S DISEASE RELATED DISORDERS ASSOCIATION, BLOOMFIELD HILLS, MI

Ms. LOMBARDO. Thank you, Mr. Chairman. I am delighted to be here.

Carol's remarks have expressed unfortunately the experiences of many people, and her wish list I think is a very articulate representation of what many of us in ADRDA are hoping that the future will bring.

I will, in my remarks, add some additional elaboration to the kinds of things she talked about.

I have been active with the Alzheimer's Disease Related Disorders Association for 6 years on the local, national, and international levels. And as many of you know, ADRDA is the only national voluntary health association which serves Alzheimer's disease and related disorders patients, families, and professional caregivers through local chapters dedicated to patient and family services, education, research, and improved public policy. We now have 143 chapters and affiliates in 44 States, and over 600 family support groups in all 50 States. I am proud to be part of this vast network of caring people.

But I am also here today, as Carol is, to speak for myself and my family. My mother has been an Alzheimer's disease victim, as you mentioned, for at least 20 years. She became a victim in her early fifties, and she is now 73. My mother was a vital, intelligent, and beautiful person and wonderful mother, and a strong contributor to the community of Schnectady, NY. Alzheimer's has robbed her of all her fine qualities, all that made her human and her life meaningful.

After 20 years, she really no longer exists as a person, and probably has not for about 10 years. Her body is alive but her brain has no intelligent or willed function.

My family and I have grieved for this woman that we love over and over again during the past 20 years, as little by little, she lost every one of her many abilities. She's been in a nursing home for over 11 years, after 9 years at home cared for by my dad, with the

help of first my grandmother, and then a terrific aide I was very lucky to find.

She has not recognized any of her family, even that we were someone that cared about her, for 12 years. I want you to get an impression of the years that are involved here. She has been incontinent for 13 or 14 years and has not walked or talked for over 8 years. The last thing she lost was her wonderful smile and that was several years ago.

So we are dealing with a very—she is not unusual. We often hear that Alzheimer's patients live only 5 to 8 years after diagnosis, but through talking with my friends in ADRDA, it seems to me that many, many live for 10 to 20 years, and so we really have to be prepared to deal with a very long-term illness.

Did you want to introduce Congressman Hertel. We are delighted that you were able to make it.

Mr. CROCKETT. No, we can wait until after you've finished.

Ms. LOMBARDO. All right.

We as a society, as Mr. Crockett, you've already mentioned in your wonderful remarks, must get our act together. We must attempt to discover the cause and hopefully a cure. We must also, for the current victims, develop an adequate and humane system of long-term care and assure that the financial burden for care is equitably shared between the family and society.

Mr. Chairman, as we all realize, the Federal agenda for action on Alzheimer's disease and related disorders is very broad. You touched on some of the areas. All of the agenda items are important and they interrelate and reinforce each other. Thanks to the wisdom of our friends like you in Congress, we have begun in making a little headway in registering the importance of action on research, education of both public and health professionals, and improved services and financial relief. But as you mentioned, we have a long long way to go before the fight is even fully joined, and before we can say that our society and our political leaders have adequately dealt with the immense set of problems Alzheimer's represents for today and tomorrow.

Unfortunately, the Alzheimer's crisis did not reach our consciousness until we were already in the middle of concerns about health care cost containment, and now we have to worry in addition about a huge budget deficit.

However, I agree with you that we cannot let these difficulties deflect us from the urgent need to take significant action now. We all feel that modest dollars spent today will help ward off catastrophe for us tomorrow, catastrophe financially and otherwise for both individual American families and for society as a whole.

Congress and our administration must carefully set our priorities so that our dollars are spent on the high-priority issues such as Alzheimer's. Today, I'm focusing my remarks on two of the Federal agenda items, research and financial relief for our families.

We need research of all kinds including biomedical research, research on which treatments work best, which kinds of modes and services and service delivery systems are better than others, and which are most cost effective for the family and for society at large.

We need research on how caregivers can be assisted in their efforts.

The Federal Government is now funding research at the $40 to $50 million level. Mr. Chairman, I couldn't agree with you more that we should be funding at the level of $500 million to $1 billion level, if we are going to achieve the results needed. But this spring, we are again facing the loss of key new research programs under Gramm-Rudman. The ax has already taken effect. At the time when we should be expanding research efforts, our Government is already cutting back from what gains were made in the Congress last year, and we're delaying very important efforts, which you will hear more about.

In addition, we are losing, perhaps forever, certain researchers who were attracted and persuaded to join the research effort on Alzheimer's disease, and are now being told that the grants that they've been assured of have been cancelled or delayed for a year or more. It seems unconscionable to me, for instance, that as a result of the Gramm-Rudman cutbacks, the National Institute of Aging has had to delay a very important Alzheimer's genetics research program by the researcher who discovered the gene responsible for Huntington's disease.

Many researchers believe that at least over a quarter of the Alzheimer's disease cases are fully genetic in origin and more and more think that perhaps all cases have at least an element of genetic cause. To delay genetic research is to me not even pennywise.

In addition to the biomedical research where we have at least a solid start, the areas of research which must be given priority attention and where today little has been done are epidemiology and health services research.

Mr. Chairman, I believe that epidemiological and health services research is essential to our efforts to begin to provide sufficient high quality and effective services for Alzheimer's disease and related disorders patients and families as well as our efforts to figure out how to develop better and more equitable methods of financing of these services.

We do not know and we must know the basic statistics for Alzheimer's disease, what is its prevalence truly, what are the incidence rates, what about geographic and age distributions, characteristics and numbers of patients at each stage of the illness, what services and treatment needs are there at each stage, and how many patients need each of these kinds of services and treatments.

Because as a society, we can't plan for services and finance them, unless we know what the needs are.

Mr. Chairman, I believe we also need public action that will guarantee the availability of and affordability of autopsy which is so essential to both diagnosis and research. We also need to know much more about which services and modes of services are preferable, and how they can be financed. A few places in Europe and the United States are experimenting with totally new ways of designing and constructing nursing homes, for example, for Alzheimer's patients, as well as innovative methods of care.

We need to study these, encourage more innovation and disseminate information about them nationwide. Research is also needed to ensure that we can develop accessibility of services to patients, whether they have families or are without families, and whatever their racial, ethnic, and socioeconomic characteristics.

Mr. Chairman, I believe that the Federal Government should take the lead in epidemiological and health services research, and in addition, it should encourage the State governments such as Michigan's to take cooperative initiatives in their own jurisdictions.

Another public policy priority beyond the research field is the financial relief for Alzheimer's disease patients and their families and for families in similar situations. As Carol has poignantly given an example of, Alzheimer's is a catastrophe, not only physically and emotionally but also financially. The cost of caring for an Alzheimer's patient who lives more than a few years is so great and the sources of financial assistance currently available to most patients and families so few that currently the disease threatens to financially devastate all but the lucky few.

As your own committee's special report of last July showed, only a year or two of home health care at $10,000 to $15,000 a year or nursing home care at $20,000 to $30,000 a year is sufficient to impoverish most elderly couples. For most patients and families, public assistance, which is usually Medicaid, is not available until the family is broke.

We need to take several actions to shift the burden for paying for services from the individual family toward society as a whole, and secure the proper balance. The family is willing to pay its fair share of the cost of care and as you can see, we have been doing it, and more.

But it is not in the interest of our society to have a system of financing that bankrupts our upper middle, middle, and lower income families and places the caregiver or the surviving spouse on government welfare themselves before patients can qualify for public assistance. We need something in the middle grounds.

We need the Federal Government, I believe, to take the following actions:

First, provide in all States, as California has already done, separation of assets between the spouses for purposes of determining eligibility for Medicaid. This seems to be a straightforward mechanism which can help prevent the impoverishment of the spouse in the family. It would also save spouses from choosing between divorce or personal impoverishment. And, really, this is really quite common. You'd be surprised how many people have to make that difficult decision.

Medicaid coverage in all States should also be expanded to encompass home health care rather than day care to help keep our patients at home and to help families like Carol's deal with the huge costs that are incurred with home health care. They still are less than nursing home care, and we want to encourage that.

Medicare coverage should be expanded to include long-term-care services, both custodial and skilled care, both in the institution and at home. And they should include Alzheimer's as an admissible diagnosis for coverage and use a means test, if necessary, to accomplish this expansion of coverage.

Make changes in our tax policies that would provide deductions and tax credits for costs of care to families supporting a family member with Alzheimer's disease or related disorders at home.

Encourage private insurance companies to generally offer policies which cover the long-term care and needs of Alzheimer's dis-

ease and related disorders patients. I think your committee is also looking at that very important issue.

State and Federal Governments and various sectors of society, including labor and business, will have to work together to ensure the feasibility and viability of such policies, but we really need them. Long-term care needs for these policies should include so-called custodial care as well as specialized or skilled treatments in nursing homes and in other settings, such as the home, day care, respite centers, or what we call here in the State, foster home care and similiar homelike settings.

We should explore through demonstration projects innovative ways to finance service delivery for Alzheimer's patients. One example is a social health maintenance organization that would include long-term-care services of all the types mentioned.

The State and Federal Governments already are spending one-half of the $33 billion spent annually on nursing home care wherein the Government's obligations are already huge. But at the same time, in 1982 families paid 45 percent out of their own financial resources. Only 1.6 percent was covered by private insurance.

The sequence has too often been, under our current system, that first the family pays until it is broke, that's the 45 percent, and then the Government takes over until the patient dies, that's the 50 percent. The surviving spouse loses the personal satisfaction of helping contribute toward paying for the care of the ill spouse, and finds him or herself without the resources for personal living costs, and remember the well spouse may have 20 more years to live themselves.

No one is happy about this situation, so we need a wiser and more humane system of financing the long-term care for Alzheimer's patients and others in a similar situation. Moreover, Mr. Chairman, as you mentioned, our allocation of money for research is shortsighted. It is too small. We are spending less than one-tenth or one-twentieth the needed level. The cost for caring for a single person like my mother is over $300,000 over her lifetime. That's a big number, yet each year, we spend on research that could lead to the cure and prevention of cases like my mother, or in the meantime provide for wiser service delivery or treatment, we spend on research only enough dollars to pay for the lifetime care of only 100 patients like my mother.

And that's kind of incredible to me. So I believe we must all join together at the Federal, and State, and local levels, and volunteer groups alike with business and industry, to find ways to provide better services for our patients, develop better financing systems, and sufficiently fund research efforts so that the cost of caring for people with Alzheimer's disease when the baby boom generation like Carol and me become elderly and at risk for Alzheimer's it doesn't bankrupt our society.

Thank you very much for holding these hearings and allowing me to make these remarks.

Mr. CROCKETT. Thank you very much, Ms. Lombardo.

We've been joined by my colleague, Congressman Dennis Hertel from the 14th ngressional District. The 14th District includes a part of the city of Detroit, all of the city of Hamtramck, and about three of the Pointes, I believe, and I think you go into Oakland

County and Macomb County, so you have a lot of public officials to account to.

Dennis is a member of our Select Committee on the Aging, and also a member of the Armed Services Committee, and I'm especially happy that he was able to make it, because I know he had to get up early this morning in order to make that early train coming into Detroit.

Have you any opening remarks, Congressman?

STATEMENT OF REPRESENTATIVE DENNIS M. HERTEL

Mr. HERTEL. Congressman, thank you. My colleagues know how hard it is to be two places at once, with so many plane delays. But it's so important to be here today to hear people's personal experiences and expertise. It is a continuing battleto change the priorities in Washington.

Late yesterday afternoon, as a member of the Armed Services Committee, I was arguing with the members of that committee against having more B-1 bombers. They've already won their fight, that all of us opposed, to have 100 B-1 bombers which are totally unnecessary. If the American people understood how backward our priorities were, things would be much different in this country.

For instance, the cost of one B-1 bomber could meet all the research money needed per year for Alzheimer's disease, alone. So we fight those battles in Washington, but I think we have an opportunity at this time to change the priorities in Washington. I think we're going to get a freeze or a cut, in fact, in the defense budget not only because of the waste and abuse, but also because so many people have begun to realize the different priorities that must be met on a higher level for our citizens.

And I think we're going to see, in this budget year, things turn around as they so very much should. Your expertise and your experiences, the figures you provide on the cost to your family and the pain to your family is representative of so many other families. This information is very helpful to us to take back to the rest of the Congress.

Mr. CROCKETT. Thank you, Congressman. That's comforting to me to have that note with respect to the military injected by a member of the Armed Services Committee.

Mr. HERTEL. Well, I see more of the waste than you do.

Mr. CROCKETT. We are reserving the question period until after we have heard from all of the witnesses on the panel, so you may proceed, Dr. Pankow.

STATEMENT OF FRED PANKOW, MICHIGAN STATE LEGISLATIVE COMMITTEE, AMERICAN ASSOCIATION OF RETIRED PERSONS

Mr. PANKOW. Mr. Chairman, Congressmen Crockett, Conyers, and Hertel, my name is Fred Pankow, I'm a volunteer member of the American Association of Retired Persons, and currently serving on our State legislative committee.

I certainly can't add to the quality of the presentation of Ms. Jones and Dr. Lombardo, but perhaps I can add something with regard to support by the American Association of Retired Persons.

Our 22 million members are certainly interested in the needs of those who have Alzheimer's disease, and their family members. I shall present a short summary, hopefully to supplement the material that's already presented to this committee, and also a presentation in writing made to the committee hearing in which you took part, Congressman Crockett, on March 21.

While experts are unsure of the exact number of persons with Alzheimer's disease, or its cause, they are agreed that the disease is strongly associated with the aging process. That is, the incidence rate rises sharply with increased age, and is most prevalent among the very old. Since the portion of the population which is over 80 is rapidly growing, the number of Alzheimer's disease victims will increase greatly in the next 40 years.

We, as a nation, must take steps now to assist the estimated 2 million persons with Alzheimer's disease now. We must also prepare to assist the even larger number of persons expected to manifest this form of senile dementia in the future. We need to undertake a multifaceted and comprehensive program of research and service delivery commensurate with the scale of the problem.

First, we should increase Federal funding for research into the probable causes, treatment and cure for Alzheimer's. Federal expenditures for research on Alzheimer's presently represents far less than 1 percent of the estimated cost of care for those with Alzheimer's. This research budget is miniscule compared to the current expenditures for research on cancer, for example.

Second, since 80 percent of all those who have Alzheimer's live at home and are cared for by family members, public policy should encourage, enhance, and support family assistance. For example, we need to greatly increase access to adult day-care and respite services in order to help relieve family caregivers of some of the burden they bear. At present, these and other vital services are not widely accessible and Medicare's home health benefit is generally restricted to those needing postacute, skilled nursing care on a part time or intermittent basis.

We also need to explore financial incentives designed to enable family based care to flourish. The direct out-of-pocket costs of long-term care for chronic illness such as Alzheimer's can be catastrophic. AARP believes that families need financial protection against these catastrophic expenditures.

While AARP will continue to explore private insurance options for long term care, we would also support an increased Medicare premium in exchange for true stop loss protection against catastrophic out-of-pocket costs for long-term care. If we are to prevent unnecessary and costly institutionalization of people with Alzheimer's, we must encourage the development and provision for a prospectively paid, case managed system of comprehensive long-term care services including adequate diagnosis and assessment.

In addition, we need to set reasonable and uniform Medicaid standards of eligibility and coverage. Since about half of those residing in nursing homes are estimated to have senile dementia of the Alzheimer's type, we can safely assume that the demand for nursing home beds will increase with the greying of our society.

The cost of nursing home care is crushing. Nursing home residents and their families presently pay for about half of all nursing

home costs. The estimated average annual cost of this care is $22,000 and accounts for the rapid impoverization of nursing home residents and their spouses. Prospective payment for nursing home care could help moderate national expenditures for nursing home care, while catastrophic long-term care insurance would help prevent this form of poverty among the elderly.

Finally, public and private groups need to help educate the public about Alzheimer's disease and the absence of long-term care. We at AARP welcome the opportunity to work with Congress, the administration, and private groups to relieve the suffering of the millions of people who have Alzheimer's and their valiant family caregivers.

Thank you, Congressmen.

[The prepared statement of Mr. Pankow follows:]

STATEMENT OF THE AMERICAN ASSOCIATION OF RETIRED PERSONS

EXECUTIVE SUMMARY

Alzheimer's disease, a leading form of senile dementia, is now thought to afflict some two million older Americans. This chronic and incurable disease creates an extensive and costly burden of care for family caregivers and society at large. But we have not met the needs of the present older generation and are ill-equipped to meet the future needs of an even larger group of Alzheimer's sufferers.

The demand for community based and institutional long-term care is growing rapidly because the portion of the population that is age 85 and older is rapidly increasing, as is the associated rate of frailty, chronic illness, and Alzheimer's disease. Yet, we do not offer victims and their families a comprehensive package of medical, social, psychological or financial assistance.

Medicare does not usually provide home health care for the chronically ill; nor does it cover the cost of care in a nursing home Since about half of all nursing home residents are believed to suffer from senile dementia, this gap in Medicare's coverage adversely affects a high proportion of our oldest old.

Furthermore, Medicare does not protect beneficiaries and their families from the crushing cost of long-term care. And, private health insurance for long-term care is not widely available.

While Medicaid does cover long-term care services, the benefit structure favors institutional, rather than home and community based care. To satisfy Medicaid eligibility rules, beneficiaries must effectively pauperize themselves and their spouses. And, states vary greatly in the amount, scope, and duration of the services they provide.

To remedy the current inadequacies in the delivery of services to Alzheimer's sufferers and their families, AARP recommends that:

1. a prospectively paid case managed system to provide coordinated and affordable long-term care services be given public support. Beneficiaries should be entitled to careful diagnosis and assessment as part of the case management system;
2. uniform national Medicaid eligibility standards and benefits should replace the current system;

3. families should be offered insurance against the catastrophic costs of long-term care for the chronically ill and frail as well as adult day and respite care. Caregiving families should also receive tax credits similar to the child care tax credit and other financial incentives to continue to provide home based care;
4. The Health Care Financing Administration should strengthen and support the 2176 Waiver program for long-term care; and that
5. increased funding for basic research into the causes, treatment, and cure for Alzheimer's disease should be made available and in rough proportion to the cost of care for victims today.

INTRODUCTION

Mr. Chairman and members of the committee, my name is Fred Pankow. I am a member of the American Association of Retired Persons' State Legislative Council. I am honored to be here this morning on behalf of the 22 million members of AARP to talk about a growing and frightening threat to the health of older Americans - Alzheimer's disease - and the concomitant crisis in long-term care.

Victims of this dreaded disease and their families need access to a comprehensive package of health and social services provided both at home, in the community and in long-term care institutions. But, neither the private or the public sector satisfies the growing need for long-term care services. An examination of the problems of those afflicted with Alzheimer's serves to illustrate the inadequacies of Medicare, Medicaid, and the Older Americans Act.

Disease Incidence: Experts on Alzheimer's disease are unable to specify exactly how many Americans presently have the disease, but its incidence is definitely linked with very old age. That is, the incidence rate increases exponentially between the ages of 60 and 85. About 1% of those age 60 are thought to have Alzheimer's, while 32% of those age 85 and older may have the disease. Since the oldest old group is the fastest growing segment of our population, it is safe to say that the number of sufferers of this disease is increasing rapidly. The 85 plus population is expected to triple in size between 1980 and 2020; an increase from 2,240,000 to more than 7 million people. The health implications of this demographic trend are

staggering if one accepts the current estimate of disease incidence. Roughly 700,000 persons 85 and older would have had the disease in 1980; while 2.3 million will be afflicted with Alzheimer's by the year 2020.

At present there is no known cause or cure for this debilitating disease which causes dementia. Alzheimer's is not in itself fatal, but it can reduce life expectancy. About half of all those with Alzheimer's survive five or six years. Consequently, all we can do is try to cope with the situation.

How well are we coping? Surveys indicate that most "cognitively impaired" older Americans live with family members who struggle valiantly with their heavy emotional, social, and financial burdens. These families need a broad range of home and community based health and social services to complement and supplement their own contributions to the care and maintenance of the Alzheimer's victim. We need to create financial incentives, such as tax credits, for family caregivers and provide a range of services designed to complement, rather than supplement, family care.

While only 20-25% of "cognitively impaired" older Americans live in institutions, surveys of institutionalized older Americans reveal that <u>half</u> of the residents in long-term care facilities have Alzheimer's and other dementias.

We also know that nursing home residents tend to be widowed and unmarried very old white females whose remaining family members are unable to provide needed care. For many of these women, a nursing home is the only realistic living arrangement because alternative community and home-based services are unavailable. That is the risk of institutionalization rises sharply with age; 22.6% of those age 85 and older live in institutions.

<u>Cost:</u> Aside from the physical and emotional toll of this disease, the financial cost to families and the nation is appalling. One study estimates that the direct cost to the nation of medical and nursing home care for Alzheimer's was about $8 billion in 1983. Much of that cost is institutional care. The costs of community and social services were even higher. (Huang, et al., "The Economic Cost of Senile Dementia in the United States, 1983", unpublished, p.16).

The need for long-term care has catastrophic consequences for individuals and their families. One study found that the annual cost of caring at home for a person with senile dementia averaged nearly $12,000 a year. The cost of nursing home care for such an elderly person averaged over $22,000 a year. (Hu, et al., "Evaluation of the Costs of Caring for the Senile Demented Elderly", The Gerontologist, forthcoming.) About half of all nursing home costs are paid directly by residents at an average annual cost of $15,000 to $20,000. Your committee found that half of unmarried residents age 75 and older are impoverished within thirteen weeks of their entry into the institution, while 75% are impoverished within a year. Spouses of institutionalized persons also face impoverishment.

Despite the enormous cost and toll extracted by this disease, current levels of support for research on Alzheimer's are very low. For example, if we spent on research only 10% of the estimated cost of medical care for Alzheimer's victims, then $800 million would be available for constructive approaches to the disease. Yet the federal government will spend only $54 million in 1986 on Alzheimer's disease research - less than 1% of the cost of medical care for Alzheimer's victims. In contrast, the National Cancer Institute spent about $1 billion last year. Surely the cost of care for those with Alzheimer's justifies a higher investment in research on prevention and treatment of the disease.

Medicare Coverage: Since Medicare primarily offers insurance protection against the cost of acute illness requiring hospitalization, Alzheimer's victims receive scant assistance from Medicare. The home health benefit is restricted to those who require intermittent and part-time skilled nursing to achieve recovery from an acute illness or accident. Under current restrictive HCFA policies, home health care is not provided on a long-term basis for the chronically ill. And, Medicare does not cover at all intermediate care facilities in which Alzheimer's victims tend to reside.

Furthermore, Medicare does not offer any protection against the catastrophic costs associated with caring for persons with Alzheimer's.

Medicaid Coverage: While Medicaid does provide some long-term care benefits, eligibility standards vary enormously, as does the range of provided services. Only eight states offer personal care services to the categorically needy; sixteen states offer this service to both the categorically and medically needy. Only two states offer unlimited services. The fourteen states which require prior authorization for part-time nursing care account for 83% of all Medicaid expenditures for that service. The thirteen states requiring prior authorization for aide services account for 83% of these expenditures; five states do not provide any homemaker services. And, where long-term care services are available, beneficiaries must satisfy a variety of "spend down" requirements in order to be eligible for service. Impoverishment and confusion are the inevitable results of this patchwork of rules and coverage.

Older Americans Act: While this Act is designed to provide a variety of non-medical home and community based services, coordination and management of these services is spotty. With the exception of some notable demonstration projects, effective case management tailored to the specific needs of beneficiaries and their families is largely unavailable.

The Private Sector: Private long-term care insurance with meaningful benefits at a reasonable cost is not widely available. For the future, increased private sector involvement in meeting long-term care needs must be forthcoming. Private insurance companies should be encouraged to add long term care benefits to existing policies and develop new policies which specifically address the elderly's long-term care needs. Over the long term, health insurance accounts (similar to tax-deferred IRAs) could be created to give younger persons an incentive to save for their future.

Public Education on Alzheimer's and Long-term Care:

AARP has joined with others in attempting to educate the public about Alzheimer's disease and long-term care options. In conjunction with the National Institutes of Health, we have made available a pamphlet on "Q & A: Alzheimer's Disease" and we are about to publish a consumer guide book entitled, "The Right Place at the Right Time: A Guide to Long-term Care Choices".

Needed Solutions: The many problems confronting sufferers from Alzheimer's disease and their families is not only a personal crisis but also a crisis for our nation. The demographic trends and projected rates of incidence for this disease are so significant that we must act now to remedy the gaps in public policy. We need to provide immediate relief to the present generation and to plan now to address the future needs of our graying society. Specifically, AARP recommends that:

- Medicare's Part A home health benefits should cover both acute and chronic conditions and provide a full array of well trained and supervised skilled personnel and homemaker services in the home;
- Medicare should cap out-of-pocket expenditures to prevent pauperization;
- expanded Medicare benefits and financial protection should be based on the insurance principles of shared risk and predictable individual cost;
- home health benefits should meet reasonable and uniform quality standards and also include consumer protection and participation;
- affordable and adequate long-term care insurance must become more readily available. AARP would support an increased Medicare premium in exchange for the financial protection against the costs of long-term care. We are also exploring the possibility of private sector long-term care insurance;
- we also recommend prospective payment for a case managed system

of long-term care based on comprehensive diagnosis and assessment;

- AARP supports the Medicaid 2176 Waiver program but deplores the Administration's restrictive regulations which hamper its operation;
- AARP also calls for uniform standards for Medicaid eligibility, as well as for the amount, scope, and duration of coverage;
- further research and experimentation into the possible causes, treatment, and cure for Alzheimer's disease should be supported. The amount of money earmarked for research on Alzheimer's disease should be a reasonable percentage of the cost of caring for its victims and commensurate with funding levels for other major diseases such as cancer and heart disease. In addition to government funded and directed research, private sector initiative should be encouraged;
- family caregivers, who provide about 80% of long-term care to the elderly, should receive financial and social encouragement and support through wider access to adult day and respite care services, removal of the one-third reduction in SSI benefits to beneficiaries living with family members, and the provision of tax credits to caregiving relatives similar to the child care tax credit.

We would welcome the opportunity to work with Congress and the Administration to design a plan which would address the critical need for long term care and better protection against the catastrophic costs of caring for the chronically ill. We believe that a comprehensive long-term care program would be in the best interest of those with Alzheimer's disease, those with other chronic conditions, and their families.

Mr. CROCKETT. Thank you very much, Mr. Pankow, and thanks to each of these witnesses.

We do have some questions. Ms. Jones, I have a question that's been going through my mind ever since I read Chairman Roybal's opening statement, in which he pointed out that in 1985, the Federal Government only spent $43 million for research in Alzheimer's disease.

I put that on one side, and then I put on another side, a letter that I recently received from a constituent literally accusing me of being unpatriotic because I didn't support the President's request for $100 million to be sent to the Contras in Nicaragua.

Now, of course that $100 million would go a long way, Dr. Lombardo, to do the research job that you spoke about and that is necessary if we're going to make any progress on this. Tell me, did I do the right thing in voting against the $100 million for the Contras and advocating more money for the research programs in Alzheimer's?

Ms. JONES. Oh, I would definitely think that you made the right move, and if in fact you asked that that $100 million be used instead for Alzheimer's research, that would have been much better.

Mr. CROCKETT. Now, I think as far as the Congress is concerned, and I'm sure that my colleagues would agree, you wouldn't have too much difficulty in getting a larger appropriation to attack the problem of Alzheimer's disease. Our problem is that the President himself cut the recommended amount from the budget of Alzheimer's disease the last time, and now we are confronted with Gramm-Rudman, which in all likelihood is going to require further cuts.

I can't escape the observation that this is an election year, and if you're going to do anything about Gramm-Rudman, we're going to have to do it at the polls. Because otherwise, I think most of these so-called social programs are going to be cut and we're going to get more B–1 bombers instead of more research.

Congressman Conyers, have you any questions, comments?

STATEMENT OF REPRESENTATIVE JOHN CONYERS, JR.

Mr. CONYERS. Thank you, Mr. Chairman.

I first of all want to thank you for your invitation here. And second, I want to comment on what the witnesses, the Jones family, AARP, which is one of the health and citizen organizations that I enjoy a great deal of support from, and my two friends and colleagues here have said. I think I'm going to say what I've got on my mind, since we didn't come here to just wallow in sentimentality about how terrible this is and how awful it is that somebody doesn't do something about it somehow.

Now let's be honest. Most people in this room supported the President, who is busy cutting Alzheimer's and everything else domestic. That's No. 1. So the problem started before somebody's mother got Alzheimer's. He was a great guy when election day rolled around. He sounded great; he carried Michigan, he carried your district, and now we're saying we've got to change the priorities.

How is this going to happen? Well, you know, we've got to take some responsibility. It's not going to happen because we jump up with a resolution in the Congress. Those days are over. There are going to be more cuts. The aging program is being hacked to bits now, as everybody here on the Aging Committee can tell you.

I was at Community Center, and the 81 lunches for the senior poor was cut and the assistants have to make spaghetti and hotdogs because of Gramm-Rudman, and that's right now. So I think we need to make this hearing reflect the problem. I think that we can do that very adequately, when I see this expert witness list; I think it can address what we really want to get to.

But then we've got to decide how we're going to really bring our Government to account, and how we can start acting 365 days of the year like we want to change Alzheimer's and not just at Crockett's hearing. Because it's not going to change this way, folks, believe me. I've been in thousands of great hearings; they line musty library walls. Nobody ever reads them again. Everyone agrees they are good for research and people who want to check it out, but it doesn't change a thing.

Now, somebody supports Reagan in the Congress, and in Michigan, and in Detroit. Somebody supports Gramm-Rudman. Somebody voted for Gramm-Rudman. Now, unless you begin to ask who in the hell is supporting Reagan and voting for Gramm-Rudman, there's no point in coming here bemoaning the fact that this is happening.

I mean, we're in a democracy. This is the one place in the world that we really are in control. But we don't want to be in control, and so we keep escaping the fact that many of our friends, many Democrats join with Reagan and many Republicans to give you Gramm-Rudman, that now everybody is against. I can't find anybody that isn't bemoaning all the cuts.

But we're being a little hypocritical, Mr. Chairman. And so we either have to say we're going to repeal Gramm-Rudman, and George Crockett is the only Member of Congress that anybody told me even said they supported my motion to repeal it; it passed by 54 votes without a single hearing. And we've got to take this law off the books. There's nothing miraculous or impossible about it.

We've made plenty of legislative mistakes. This is one of the more gross, and we've got to get a committee to repeal Gramm-Rudman, and it's got to come out of Michigan and all the other States that people are suffering in. When we do that and call everyone into account, well, hold onto your seats, all of our friends who voted for Gramm-Rudman. I'm sick and tired of walking around seeing my Democratic Congressmen and Senators Levin in District 17, Senator Levin, the former president of the council, all who voted Gramm-Rudman, sit with me and tell us how bad Gramm-Rudman is.

Now, either we're all adults or we're just going to fool ourselves, and I'm a little tired of everybody acting like Gramm-Rudman is so impossible to deal with. We put it on the books; we can take it off the books, and it's not going to be taken off in the Congress by a few Members of Congress. It's going to be taken off by AARP giving the word. It's going to be taken off by the Michigan Associa-

tion of Alzheimer's laying down the law, and calling us all into severe account.

And I hope I haven't upset anybody too much with my personal view of what we've got to do in this matter.

Mr. CROCKETT. Thank you, Congressman.

Congressman Hertel.

Mr. HERTEL. Well, I want to thank the people on the panel for their testimony to help us change our priorities. And I'm ready to hear the next panel.

Mr. CROCKETT. Thank you.

Susan Rourke, David Hollister, Gloria Smith, Zaven Khachaturian.

Will everyone please be seated. I want to welcome each of the witnesses on this panel.

We will begin with you, Ms. Rourke. Ms. Rourke is executive director of Citizens for Better Care. You may proceed.

Ms. ROURKE. Thank you very much.

STATEMENT OF SUSAN ROURKE, EXECUTIVE DIRECTOR, CITIZENS FOR BETTER CARE

Ms. ROURKE. Thank you very much, Representative Crockett, Congressmen Conyers and Hertel. I'm pleased to be here today, and I will be speaking from the point of view of Citizens for Better Care which has sponsored the State's Long-Term-Care Ombudsman Program with a number of local ombudsman programs throughout the State since its inception with Federal funding.

And from our perspective, as we handle complaints about nursing home care, as we assist families, almost 5,000 a year, in finding placements in nursing homes that offer long-term care settings, I'd like to confirm and underline the earlier testimony of Dr. Lombardo and Ms. Jones in some of the difficulties that are most acute for Alzheimer's patients, but which are faced by a number of persons who are older.

There are three issues that I want to touch on; the first one is the whole issue of diagnosis which has been talked about a little bit.

And the second issue is the issue of difficulty of finding services, and the third is the ongoing difficulty about quality of care.

In the area of diagnosis, you know, we really don't deal very well with crazy people. We don't like them; they're not like us; we're scared because we're going to become like them. All of the fears of becoming an Alzheimer's victim or someone who has lost their ability to make decisions really sets the tone for how persons like this are treated through institutional services.

We at Citizens for Better Care are concerned that an agenda be set, as you are setting the Federal agenda for Alzheimer's disease victims, and that the agenda include all elderly who have the care needs and behavioral problems similar to Alzheimer's victims. We must not create a separate set of services that are eligible only through the diagnosis of Alzheimer's. We are also concerned that anxious families and untrained health providers not rush to the diagnosis of Alzheimer's disease in order to use new programs or dollars, thereby overlooking other conditions which may be reversible,

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such as depression, drug interactions, nutritional and metabolic problems, and other conditions which produce the same behaviors.

Finally, families with few resources, poor families or families in rural areas are really unable to confirm an Alzheimer's diagnosis. Because of the length of time it takes, the kinds of testing we have are really not available to most people. In some cases, families are quick to use the concept, the words, Alzheimer's disease, because the diagnosis has become more socially acceptable than alcoholism, severe depression, or schizophrenia.

We believe that research should very quickly move and be funded to look for diagnostic tools and treatment; however, we feel the care programs of all elderly persons who are disoriented and confused need to be improved and available to them, regardless of diagnosis or economic conditions.

In the area of services, as we look at the continuum of care, a nice word that the professionals use for the elderly, we find there are holes in it for most elderly people and the holes have been exacerbated, not only by the Gramm-Rudman-Hollings Act, but certainly by the current situation in the medical field, the pressure of early release from hospitals caused by the hospitals' behaviors in response to the diagnostic related groups or DRG's.

Those holes in this long-term care system are huge gaping holes if the older person is disoriented, confused or aggressive. First and unique to the Alzheimer's patients, who may have their problems beginning in their fifties, they are not eligible for most of the continuum care for older people. Most of the Older American Act funded programs have an age eligibility.

Second, as I think earlier people have said, early mild cases of the Alzheimer's disease or related problems are most often cared for at home by family members, for whom there is little or no respite care. And you've heard extensive testimony and moving testimony earlier on that.

I think the other piece to know, though, and the theme that runs through all of the care is that it is expensive. It's expensive in the lives of the people who give it, and it's expensive in the dollars they must pay for it.

Day care centers have been lifesavers for families by allowing a normal work life and some limited respite care from the demands of the total supervision of a disoriented relative. Unfortunately there are far too few day care centers, and many are far too expensive for low-income families. And again practically none of them may take someone who is incontinent or moving into some more difficult management problems.

In addition, in-home care services and community services currently provided by the aging network have already been cut this current fiscal year we're in by the Gramm-Rudman-Hollings Act. Home chore, home help, home health services are a bag of services which really are not easily available; they are not reimbursed under Medicare for custodial care, and they generally must be paid for by the family themselves.

If placement in a facility is needed, then the least restrictive and most humane setting is an adult foster care facility, certainly, as they are small and family like. However, adult foster care facilities are often willing to take SSI in many areas, which is about over

$450 a month in Michigan. However, with the growth of interest and concern about Alzheimer's disease, we are aware of adult foster care facilities that are charging between $1,500 and $1,700 a month for care in an adult foster care facility, when our State only pays $1,200 a month for nursing home care.

It's a big market, selling care for Alzheimer's victims.

In addition, there are some areas in the State where elderly persons dependent on SSI cannot find an adult foster care bed. In Oakland County, which is immediately north of here, of Detroit and Wayne Counties, the majority of adult foster care facilities are private pay. Poor people may not need to apply.

Homes for the aged which provide personal care and supervision seem like a logical alternative for the slightly disoriented older person. Unfortunately, few will take SSI, and more importantly, none of the freestanding homes will accept persons with any kind of disorientation. The owners tell us there is a marketing problem or unrealistic working problem. Folks don't want to see old confused people in place where they are going to be spending their days.

So nursing homes then become the choice for some people who cannot pay privately and for most persons in the later stages of the disease. A survey of Oakland and Macomb County nursing homes indicated that a number of homes specifically prohibited Alzheimer's or patients who have some sort of behavioral disorders. Most will not take any person who is aggressive.

Once again, as in adult foster care, we're seeing nursing homes and nursing home units which specialize in the care of Alzheimer's disease. In most cases, only for private pay. Medicaid does not pay. A family with an older person who is confused, disoriented, or aggressive has a limited and decreasing number of services available to them in the community.

If a person is diagnosed as suffering from Alzheimer's disease, the family has more choices if they are able to pay privately. The current situation points to a continuing combination which is characteristic of the provision of formal long-term care services: Poor care for the poor and financial exploitation of the rest of us until you are poor.

Regarding the whole issues of quality of care, I must point to the Institute of Medicine study which recently reported to the Congress, based on a congressional resolution. The first finding that they had is the quality of care and the quality of life in many nursing homes is not satisfactory. We find that again and again, as we visit in homes. At one point, the Michigan Department of Public Health defined a large number of homes where the care was so poor that it needed regular onsite supervision by the Michigan Public Health Department.

The vast majority of nursing homes are only mediocre; there are some that are quite good and most of them are just barely meeting the standards. And those residents that are confused and disoriented are most at risk because they are unable to state their needs and to assure that their care is met.

The State Long-Term Care Ombudsman Program report for which Citizens for Better Care has provided, indicates that most of our complaints from families are about care problems.

When we visit nursing homes, even those homes that are able to provide minimum physical care do not meet the emotional needs of the people. Staff do not know the names of the residents in some homes. They don't organize a life that has quality.

The recommendations that we would have are very much along the line as others.

We urge that you establish and fund reasonable amounts of research to find the treatment, the diagnostic tools and treatment for Alzheimer's and related diseases. However, we really feel that you ought to tie the care options to current network, the aging network. A whole variety of programs that are out there now are underfunded.

The programs through Medicaid and Medicare need to be expanded to include Alzheimer's victims. We do not have to set up a separate system. Too many old people suffer from a variety of diseases and problems and to create a separate system, I think, would not serve most older people.

We urge that you look at the Institute of Medicine study which was recently released by the National Academy of Sciences, which has several really just beginning steps to make changes in the quality of care and the quality of life in nursing homes.

We also urge that you require funding for training and supervision for professionals and aides in nursing homes and other settings to be able to handle the mental health needs and the kinds of aggressive patient behaviors that many persons with Alzheimer's disease have, and that such training and supervision be required as a condition of institutional licensure.

Finally, I believe the reorientation of our value system for providing care for old people regardless of their needs, economic needs or otherwise, which the Congressmen have already spoken about, is severely needed.

Thank you, very much.

[The prepared statement of Ms. Rourke follows:]

PREPARED STATEMENT OF SUSAN ROURKE, EXECUTIVE DIRECTOR, CITIZENS FOR BETTER CARE, DETROIT, MI

Good morning, my name is Susan Rourke, and I am Executive Director of Citizens for Better Care which is a seventeen year old state wide consumer agency concerned with the quality of care in Nursing Homes, Homes for the Aged and Adult Foster Care Homes, as adult board and care homes are called in Michigan. Since the early 1970's CBC has sponsered the state Long Term Care Ombudsman program and local ombudsman programs; in addition, CBC assists callers in selecting a nursing home and, where appropriate, alternatives to nursing home care. Today I will talk about CBC's experiences in finding services and care for persons who have been diagnosed as having Alzheimer's disease or those whose problems and behaviors are similar to those Alzheimer's Disease. Specifically, the issues are problems with diagnosis, finding services and getting decent care.

In the area of

DIAGNOSIS

We don't like crazy people; we as a society reject those who are disoriented and confused, we send them to the county poor farm - or its modern cousin the nursing hoem - and to the state mental insitutions. Their "otherness" is frightening both in the loss of the individual personality we know and in the potential of our becoming that way. Fear of aging includes not only the loss of physical powers, but the fear of loss of "self", of being old and "senile".

And of course, this problem is not a new one. Vladeck reported in Unloving Care (Basic Books, New York, 1980) that in 1930 more poeple over 65 lived in mental hospitals than in poor houses and private retirment homes. Today in Michigan the mental health code states that those over 65 cannot be admitted to state mental hospitals for diseases associated with age or senility. In spite of this there are still 440 people over 65 in those institutions which Ralph Nader's group recently found to be among the worst in the nation.

We also know, and studies have confirmed, that "senility" is one of the major determinates of nursing home care. The 1977 National Nursing Home Survey found that nursing home residents had multiple diagnoses and the two primary catagories were diseases of the circulatory system and senility; and, that those likely to stay the longest were those who were diagnosed as having mental illness or being senile, along with being poor and isolated. (GAO, Medicaid and Nursing Home Care: Cost Increases and the Need for Services are Creating Problems for the States and the Elderly, October 21, 1983).

Why all of the discussion about "crazy" people, about mental illness before a group who are "setting an agenda" for Alzheimer's disease? We are concerned that an agenda be set for Alzheimer's disease victims that includes the elderly whose care needs are the same as those of Alzheimer patients. We are also concerned that anxious families and untrained health providers may rush to the diagnosis of Alzheimer's in order to use new programs or dollars and overlook other conditions which are reversible such as depression, drug interaction, nutritional and metabolic problems and other conditions which produce the same behavioral characteristics as Alzheimer's disease. Strokes and other circulatory problems may also create the difficult behaviors which lead a family with few resources, for instance in a rural area or on a limited income, to be unable to confirm the Alzheimer's disease diagnosis. In some cases, families are quick to use the words "Alzheimer's Disease" because that diagnosis has become socially acceptable unlike alcoholism, severe depression or schizophrenia. We believe that research should move ~~quickly~~ to look for better diagnostic tools and treatment; however, we feel that the care and treatment of all elderly persons who are disoriented, confused, and "difficult" needs to be improved and available to them regardless of diagnosis or ~~financial~~ economic condition status.

SERVICES

As we look at the "continum of care" for the elderly, we find that there are holes in it if one is disoriented, confused or aggressive. First, and unique to Alzheimers patients who may be diagnosed in their 50's, is that many of the programs are designed and paid for by Older Americans Act dollars which has an age eligibility ~~of 60.~~ Second, early mild cases of Alzheimer's disease are most often cared for at home by family members for whom there is little or no respite care, ~~that~~ which is available is expensive, a theme which runs through all of the care for mentally disabled persons.

Day care centers have been life savers for families by allowing a normal worklife to continue and to offer limited respite from the demands of care for a disoriented relative. Unfortunately, there are too few day care centers, many are too expensive for low income families and finally, practically none of them take persons who are incontinent. In addition, in-home and community services currently provided by the aging network have already been cut this current fiscal year, and may be cut even more drastically under Gramm Rudman Hollings Act.

If placement in a facility is needed, the least restricitve and most humane setting is an Adult Foster Care ~~home~~ facility which may be small and family-like in atmosphere. Adult

Foster Care facilities in many areas provide care for the confused elderly and are willing to take the Supplemental Security Income (SSI) level of reimbursement, which is over $450 a month in Michigan. However, with the growth of concern and interest in Alzheimer's disease, we are aware of Adult Foster Care homes which specialize in caring for Alzheimer patients - at $1500 to $1700 per month which is more than the average $1200 a month which the state pays nursing homes for Medicaid patients. In addition, there are some areas in the state where elderly persons dependent on SSI cannot find an Adult Foster Care bed; in Oakland County which is immediately north of Detroit and Wayne County, the majority of homes are "private pay" - poor need not apply.

Homes for the Aged which can provide personal care and supervision would seem like logical alternative placements for the slightly disoriented older person. Unfortunately few will take SSI and more importantly none of the freestanding homes will accept persons with any kind disorientation or mental problems. The owners tell us there is a "marketing" problem; residents and new applicants to the home do not want "crazy" or disoriented old people around.

Then, nursing homes must be the choice for some poeple who cannot pay privately and finally for most persons in the later stages of the disease. A survey of Oakland and Macomb county nursing homes indicated that a number of homes specifically prohibit Alzheimer's patients, and most will not take persons who are aggressive. Once again, as in Adult Foster Care, we are seeing nursing homes and nursing home units which specialize in the care of Alzheimer's diseas - in most cases only for those who are able to pay privately.

The family or older person who is confused, disoriented and/or aggressive has a limited and decreasing number of services available to them in the community. If the persons is diagnosed as suffering from Alzheimer's disease, the family has more choices if they are able to pay privately. The current situation proints to a continuing combination which ~~has~~ is characterized the provision of formal long term care services - poor care for the poor and financial exploitation of the rest until they are poor.

QUALITY OF CARE

Part of our aversion to the mentally confused is that we don't know what to do. There are trained professionals specializing in the treatment of Alzheimer's patients, and the mentally ill, but their skills and managment techniques are not widely practice by the undertrained and poorly supervised staff in most nursing homes.

The first conclusion of the Institute of Medicine report on nursing homes released in March of this year is" "Quality of care and quality of life in many nursing homes are not satisfactory". CBC's experience confirms that over and over. There are a few very good homes, a number of very poor homes (at one time recently the Michigan Department of Public Health had identified 23 homes as needing on site supervision because of care problems - and several others for which they were considering license denial).

The vast majority of nursing homes are only mediocre; they are just barely meeting the licensing requirements. And, those residents who are confused and disoriented may be the most at risk as they may not be able to make their needs clear. The State Long Term Care Ombudsman report for the most recent year indicates that complaints about care are the most common problem reported to CBC.

When my staff and I visit nursing homes we find staff that may not know a confused patient's name. We find disoriented patients all exiled to sitting in the same day room strapped to their chairs, forgotten until their physical needs must be met. The staff is not trained or rewarded for spending time with difficult patients, and "activities" occur in a room in the basement; it is separate, not a part of ongoing quality of life in a nursing home. A recent complaint we received from a nursing home about treatment of an Alzheimer's patient is characteristic of the nursing home's responses. A patient in a nursing home suffering from Alzheimer's disease was a farmer most of his life. The first day of spring arrived this year, warm and sunny. The patient's first response was to try to go outside. The nursing home staff was concerned about the possibility of the patient wandering away. The attempts of the patient to go outside became increasingly aggressive, and the staff resorted to chemical restraints, to durgging the patient into manageability. Was this the only choice? I think not. I believe that a nursing home with sufficient staff, training and supervision might have found a humane way to meet the individual needs of this patient - something as inexpensive as a supervised walk out of doors, as feeling the sunshine and warmth of the first day of spring.

CONCLUSIONS

We feel that the special problems of Alzheimer's patients need to be addressed along with the problems of the disoriented, confused and aggressive elderly. There should not be special sprograms by diagnosis but by treatment and care needs. We urge you to:

1) Protect and expand the funding for in home and community services for the elderly. This certainly includes chore services, meals programs, day care, respite care, and protective services such as the ombudsman program. We also urge you avoid the increasing "medicalization" of long term care services which is happening because of the routes for reimbursement and the increased involvement of hospitals in the field.

2) Examine the Institute of Medicine study Improving the Quality of Care in Nursing Homes, and translate the recommendations into legislation. It certainly represents a first consensus step toward quality of life for nursing home residents; there are further reimbursement systems to meet individual needs such as the case-mix systems now operating in Ohio, Minnesota and New York among other places.

3) Assure that training in handling "difficult" or mentally ill patients - regardless of diagnosis - is a requirment for all health professionals (doctors, nurses, etc.) who deal with the elderly, and that ongoing training and supervision of nurses aides and orderlies is required as a part of certification for the facility's and individual's licenses.

4) Finally, assure that programs are available to people who need them, regardless of social or economic status.

Thank you.

michigan long-term care

Ombudsman Update

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Resident Care #1 Complaint

In keeping with the Congressional mandate, the major focus of the Michigan Ombudsman network during fiscal year 1985 was the resolution of the problems of Michigan's 47,000 nursing home residents. The State Long-Term Care Ombudsman Project (SLTCOP) recently reported on the work of the SLTCOP and the six local Ombudsman projects in Michigan.

During the year, Michigan Ombudsmen addressed 717 separate cases involving 1300 individual complaints or problems. Most of the issues (66%) were resolved in some fashion by Ombudsman staff. One quarter of the complaints were referred to the Michigan Department of Public Health for investigation and action.

Not surprisingly, resident care was the most frequent reason Ombudsman assistance was sought. Almost 40% of the 1300 complaints concerned inadequate hygiene care, bedsores, lack of restorative nursing, residents falling, physical abuse, improper restraints, and similar care complaints.

The second most frequent kind of complaint involved the administration of the home. Eighteen percent (18%) of Ombudsman complaint work concerned understaffing, admissions practices, transfers, bed holding policies, illegal private pay duration of stay contracts, and other administrative actions by homes.

The great bulk of the remaining 42% of complaints were almost equally divided among five other major complaint categories: food and nutrition; financial issues; resident rights; building, sanitation and laundry issues; and complaints against agencies or people other than the homes and their employees. Ombudsmen also investigated a small number of complaints concerning physician services and medications.

Of the 140 different kinds of complaints handled by Ombudsman staff, 15 represent 32% of the total workload. The top 15 complaints in order of frequency were:

1. Inadequate hygiene care
2. Understaffing
3. Questionable financial charges
4. Bedsores
5. Lack of restorative nursing
6. Personal items lost, stolen, or used by others
7. Physical abuse

Residents Prevail at Huron View

The Michigan Department of Public Health (MDPH) recently ruled that two nursing home residents could not be evicted from Huron View Lodge in Ann Arbor.

In the summer of 1985, Huron View notified MDPH that it was voluntarily leaving the Medicaid program. The home sent notices to its Medicaid residents that they had to leave. All but two of the Medicaid residents left the nursing home.

Under Michigan law, a nursing home resident cannot be "involuntarily transferred" except for medical reasons, for non-payment, or for the welfare of the resident, employees, or other residents.

Two residents and their families fought Huron View's contention that they could be evicted for non-payment. Represented by attorneys from Legal Services of Southeastern Michigan, the residents argued that since they were continuing to pay their individual portions of the Medicaid rate and the state was willing to continue paying its share there was no non-payment. The residents' advocates also pointed out that an eviction would be very damaging to their health.

MDPH Director Gloria Smith agreed with the residents. She stated that the nursing home did not "demonstrate non-payment" for their care and that the home could not transfer the residents. The home did not appeal the decision.

Complaints, cont.

8. Residents falling
9. Improper restraints
10. Neglect
11. Staff attitudes
12. Admissions procedures
13. Discharge plans, procedures
14. Improper transfer, not related to Medicaid
15. Bed not held during hospitalization

Other than their work on complaints, Ombudsmen assisted over 2400 people in finding a nursing home placement or other long-term care facility or service. Another 1000 people and agencies were provided technical assistance in answering questions about the long-term care system. During the year, 4000 people attended trainings or speaking engagements of state and local Ombudsmen.

Credits

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If you would like to be added or removed from the mailing list, please notify us at: Long-Term Care Ombudsman, 1627 E. Kalamazoo, Lansing, MI 48912, (517)482-1297 or (800)292-7852.

Mr. CROCKETT. Thank you very much, Ms. Rourke.

Our next witness is Ms. Gloria Smith, who is director of the Michigan Department of Public Health.

Welcome, Ms. Smith. You may proceed.

Ms. SMITH. Thank you, very much.

STATEMENT OF GLORIA SMITH, DIRECTOR, MICHIGAN DEPARTMENT OF PUBLIC HEALTH

Ms. SMITH. Mr. Chairman, and members of the select committee, thank you for coming to Michigan to hold these important meetings on Alzheimer's disease. I wish to make a few brief remarks, and ask that my written statement be inserted into the record.

Mr. CROCKETT. Without objection.

Ms. SMITH. Thank you.

Concern over Alzheimer's disease has greatly expanded in the last 5 years. At least 10 other States have initiated major efforts and we are glad that Governor Blanchard and key legislators in Michigan have recognized the seriousness of the problem.

Indications are that there are approximately 100,000 people ill with Alzheimer's disease in Michigan. As has been underscored repeatedly this morning, we are recognizing that mental deterioration is among the most devastating and dreaded disorders of old age. While we once thought of this as a natural part of the aging process, we now know that this is untrue.

Alzheimer's disease affects 5 to 7 percent of people over age 65. It is characterized by a steadily eroding memory; while at first the loss is minimal, the disease is progressive and is often accompanied by a loss in the ability to perform the daily tasks of living, such as dressing, bathing, or eating.

I wonder as we listened today if anyone who has not been through this experience can really understand what it is like to face an unending succession of days caring for someone who used to be a loving and thoughtful companion but who is now a diseased stranger who often acts like a hyperactive child and will likely become a true geriatric tragedy.

Both the patient and the family are victims of Alzheimer's disease. Thus, interventions must be aimed at both parties and can be directed toward solving those aspects of the problem that can be changed. Alzheimer's disease will increase, as has been reported here this morning, as the population of Michiganians over age 65 increases.

This means that the current 100,000 sufferers will double to 200,000 by the year 2000. Areas of the State with the greatest increases are likely to be those with the fewest resources to cope, namely the inner-city and rural areas. We will be using the task force approach in Michigan to collect definitive information on needs. We will also document the level of existing services and identify gaps in the current service structure.

By this time next year, recommendations will be forthcoming on standards of care, reimbursement systems, training and research.

Governor Blanchard and the legislature are awaiting our findings and I'm confident that they will move in the spirit of bipartisan cooperation to alleviate this suffering. Permit me in the re-

maining moments of my time, to point out some needed Federal directions—sorry, Congressman Conyers—and support.

Mr. CONYERS. You better worry about some State directions.

Ms. SMITH. Right. I agree with you.

But the State directions, I think that we are going to get support from our legislature, but it is clear that much of that needs to be dealt with within the context of changes that have to occur at the Federal level.

It is essential for all levels of government, Federal, State and local, to identify and carry out their respective responsibilities. We in the States believe that the Federal Government should support patients and caregivers with third party reimbursement systems that promote the least restrictive health care and living arrangements possible at any point in the course of the disease.

Help should be given before families become emotionally and financially destitute. And we heard that several times this morning. Let the Federal Government pay for services such as homemakers, in-home nursing, and day care. Let a tiered system of nursing home care be fully covered, based on patient and caregiver needs.

We're talking about trying to make our system more effective, more efficient than it currently is. The Federal Government also should make available cooperative arrangements or formula grants to the States to plan, promote, and coordinate health care services to victims of Alzheimer's disease. It will do no good to pay for services if they are nonexistent.

Public health departments blanket the Nation. Virtually every county in the United States is covered by a unit of local public health. We specialize in delivering services to vulnerable population groups in hard to reach inner cities and rural locations. Given the responsibility and the resources, we in public health would like to be a part of the solution. Most of us hope that we will have a long and vigorous life, culminating as in Oliver Wendell Holmes' "Wonderful One-Hoss Shay," with a sudden terminal collapse; vitality until the end, and death coming without fear or fury as the natural end of our individual lifespan.

For many of us, it will not happen this way. Realizing that but for the grace of God go we, let us collectively resolve to help the victims of Alzheimer's disease and their families.

Thank you. I would be glad to answer questions later.

[The prepared statement of Ms. Smith follows:]

PREPARED STATEMENT OF GLORIA R. SMITH, PHD., M.P.H., F.A.A.N.,

DIRECTOR, MICHIGAN DEPARTMENT OF PUBLIC HEALTH

Mr. Chairman and Members of the Select Committee:

Thank you for holding this hearing in Michigan and providing an opportunity for me and others to inform the Committee about the status of Alzheimer's Disease and our plans for meeting its challenge.

In a suburb of Lansing about 15 years ago a woman worried about her mother. A strong, capable woman in spite of her 70 years, her mother had always been an excellent housekeeper who had kept herself and her affairs in perfect order. Now there were disquieting signs that something was wrong-she was letting the house go, the refrigerator was a mess, and she had given up caring for her personal appearance. During the next two years the daughter's fears worsened as her mother's condition deteriorated.

Eventually it became clear she could no longer live independently and care for herself. The physician who examined her offered no clarification or relief, and called her condition senility. Since there were no supportive services available in the small Canadian town where she lived, the mother came to live with her daughter in Michigan.

To telescope the next ten years' experiences, the mother did well in her daughter's home, where someone could be with her most of the time and help her complete the chores and tasks she had begun, like bathing, dressing and combing her hair, which she was not able to carry through otherwise.

In 1978 an "absolute godsend" took place, according to the daughter, with the opening of the of the Lansing adult day care center. Her mother, who has now been going there three days each week for the past eight years looks forward to spending her day there. The county-operated senior citizens transportation program provided very helpful door-to-door bus service one day a week, while the daughter drove both ways the remaining two days.

The staff of the day care center, who are very good and caring with their clients, haven't received any special training in caring for Alzheimer's Disease patients to this day, even though about half of the 25-30 clients of the Center apparently suffer from the disease.

The outcome has been as good as can be expected. The mother is active and alert at age 86. The daughter has become a strong advocate for Alzheimer's Disease patients and their families, and serves on the Board of Directors of the day care center in addition to running a successful company. She is also planning to testify at this hearing today.

The personal story I just related to you is a truthful account of how one family, with loving care, adapted to a condition which has been ignored or swept under the carpet for years by the helping professions. We are told that there are 100,000 other cases of Alzheimer's Disease in Michigan, most of them in less fortunate circumstances as when the patient manifests the common symptoms of sleeplessness and wandering off, which was not the case with the patient in my example. Such behavior can make it impossible for the caregiver to get proper rest needed to maintain the strength and energy to cope with their patient every day.

I wonder if anyone who has not been through this experience themselves can really understand what it is like to face an unending succession of days caring for someone who used to be a loving, caring, and thoughtful companion. Now the person is a stranger, acting like a hyperactive child often without judgment or forethought, and with a prognosis of eventual deterioration to a vegetative state.

The Need

The large and growing numbers of patients and affected family members makes this a serious public health problem, one which is closely linked with how well we can care for the aging in general, and thus with tremendous implications for the future. If our population projections hold true, the number of Alzheimer's Disease sufferers is expected to double by the year 2,000. Areas of the state with the greatest increases of elderly will be those with the fewest resources for health and welfare services. Inner city residents who are trapped by poverty, ignorance and fear and persons in the rural parts of the state, where the problem is lack of access because of low budgets and high unit costs of delivery are especially vulnerable.

Probably the greatest obstacle among the broad gamut of problems associated with Alzheimer's Disease is the lack of reliable early diagnostic method. The only definitive diagnosis possible now is microscopic examination of brain tissue after autopsy, which largely explains why Michigan's cause-of-death statistics for Alzheimer's Disease are so inadequate. Even when secondary and related causes are taken into account, the number of Michigan deaths from this condition for the most recent five years on record, from 1980 through 1984, were 30, 53, 64, 111, and 141. We expect the true annual mortality to be approximately 4,500.

The understatement of mortality tells much more of attending physicians' lack of knowledge and awareness of the characteristics and symptoms of Alzheimer's Disease than the true numbers of deaths from the condition. Good data is absolutely vital in understanding the consequences of any disease and developing a plan for its prevention, management and control. Short of a simple, inexpensive reliable early diagnostic test, a uniform standard definition of behavior indicative or presumptive of Alzheimer's Disease needs to be developed and given wide dissemination through professional education channels. A model for continuity of care with particular emphasis on such elements as adult day care and respite care must be clearly defined so that gaps in necessary community and institutional services can be noted and corrected.

Dr. Victor Hawthorne, Chairman of the Department of Epidemiology at the School of Public Health, University of Michigan, discussed in a recent paper the widespread concern regarding standards of care and housing for deinstitutionalized mental patients including many Alzheimer's patients. He underscored the lack of coordination and confusion of responsibilities between mental health, public health and social services (1). This confusion and lack of coordination, lies at the root of many problems confronting the Alzheimer's patient and family. Other points made by Dr. Hawthorne, who is also a member of our Chronic Disease Advisory Committee, are the urgent need for public awareness" of the magnitude of the problem, which is reaching pandemic proportions and for which the public must take greater interest and physicians and legislators much greater responsibility."

The myriad of needs must be organized and prioritized before we can proceed further to the stage of analysis and then proposing solutions. The approach taken by the State of Michigan resulted from simultaneous action by the legislative branch, the executive branch, and a concerned, knowledgeable, and well-organized group of citizens through the Michigan unit of the Alzheimer's Disease and Related Disorders Association.

Activity in Michigan

In December, 1985, the State House of Representatives and the Senate passed a Resolution urging the Michigan Department of Public Health and the Chronic Disease Advisory Committee to appoint a task force to study progressive neurological diseases, with particular reference to Alzheimer's Disease, and create programs to assist victims of this disease at the state and national level (2).

This action was followed in January, 1986, by Governor Blanchard's State of the State address, in which he called attention to Alzheimer's Disease as a critical health problem in Michigan. He assigned the Human Services Cabinet the task of identifying "the key issues surrounding Alzheimer's and other related disorders and to formulate recommendations for the state" (3).

The Human Services Cabinet, consisting of the heads of the major health and welfare agencies of state government, responded to the Governor's charge in February and named the Department of Public Health the lead agency to carry out the effort. I am working closely with the Chronic Disease Advisory Committee, whose members are appointed by the Governor and confirmed by the Senate, in the establishment of the Task Force on Alzheimer's Disease and Related Conditions.

The Michigan Task Force will be chaired by Joyce Kortman, a distinguished citizen and member of the Chronic Disease Advisory Committee, and its first meeting has been called for May 2, 1986. The proposed membership includes representation from the major professional and lay groups interested and involved in Alzheimer's Disease and related conditions.

The Task Force will operate over the space of one year and will be staffed by the Department. The charge includes assessing existing epidemiological evidence on Alzheimer's Disease in Michigan; identification of the wide range of patient and family needs, available resources, and service gaps; defining standards for levels and placement of treatment, plus studying alternative methods of payment for the long-term costs of care; assessment of the quality and quantity of specialized training and education for health care personnel members of the general public and important subgroups; investigation of related moral and ethnical issues, plus the major legal questions involved; and finally, identifying the specific research needs necess to support the state program recommendations.

In terms of other Michigan activities, a significant study has been planned and a pilot has just gotten underway to look at the needs for long term care in the Upper Peninsula, the most sparsely settled part of Michigan, with over a quarter of the land area and 3% of the population. The study, a coordinated effort by my department, local public health and the Office of Services to the Aging, includes a review of home care and supportive services with the ultimate purpose of allowing the aging the opportunity to remain as independent as possible for as long as possible. Although not directly aimed at Alzheimer's Disease, the results of the study and its recommendations promise to be important steps in our efforts to meet the needs of the Alzheimer's patient and family in rural Michigan.

There are several other pilot studies either being planned or now underway by a variety of sponsoring and funding organizations, which have implications for improved care for Alzheimers patients and families. The Greater Detroit Area Health Council is coordinating the planning and support of two different models of social health maintenance organizations in Metropolitan Detroit. The operation of these pilots over a period of time promises to answer many questions related to continuity of care and related costs. The State Department of Mental Health has funded a pilot respite care project with the Detroit office of the Alzheimer's Disease and Related Disabilities Association, who will train, supervise and schedule volunteers to relieve home-bound caregivers for a period of time each week.

Federal Help Needed

Support from the Federal Government is absolutely essential for progress in improving Alzheimer's Disease services in Michigan. The states rely on the federal government financial support of new health initiatives in general, and especially for funding and of the continuing basic research into the causes early identification and prevention of Alzheimer's Disease and related conditions. The funding of pilot studies of new treatments, flexible long-term care services and insurance, and home care incentives are all most appropriately conducted at the federal level.

Changes and clarifications in the rules and regulations on eligibility and coverage by Medicare, Medicaid, the Social Security disability programs, and Veteran's Administration health services are needed to assure the fair and equitable distribution of resources to Alzheimer's patients and families. Services that will have greatest effect on improving their quality of life must be supported.

Finally, federal influence and support of appropriate training and education programs can be instrumental in shaping the health and welfare systems of the future to better handle the problems related to Alzheimer's Disease.

Future Directions

The Department and I are banking heavily on the recommendations to be forthcoming from the Michigan Task Force on Alzheimer's Disease to tell us in which direction we should go. However, some items already cry out for attention. The most important services needed today are respite services and adult day care. Accepting the idea that care by the family at home is the best and most cost-effective method, these modalities become very attractive ways of maximizing the family's capability of caring for their loved one. The state's role then becomes one of establishing model programs adapted to different conditions found about the state, and then training appropriate staff persons to direct and work in these programs.

Since respite care can be established with the use of trained supervised volunteers, it may be possible to implement such a program inexpensively in both urban and rural areas through local public health, mental health or social service agencies.

Adult day care programs serve a variety of human needs and their staffs require specialized training to meet the various needs of Alzheimer's patients. Also, the entire educational system will be called upon to help us understand and serve the needs of the fast-increasing older generation.

To summarize, Alzheimer's Disease patients and their families present us with both a challenge and an opportunity. The challenge is to pull together all the fragmented, disjointed services in each of our communities, adding services that are missing and making sure they all work together so that persons receive the level of care and support they need to live out their years in good health and security, regardless of their mental and physical status.

The opportunity is to carry out the promise of a great state and nation to the people who worked hard to make it so, and in the process affirm our own values and ideals of what successful living should be in our later years.

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2. State of Michigan: House Concurrent Resolution No. 591. Adopted by the House of Representatives Dec. 17, 1985. Adopted by the Senate Dec. 18, 1985.

3. Governor James J. Blanchard: State of the State Report. The Michigan Strategy: Fourth Year of Progress. January, 1986, page 56.

Mr. CROCKET. Thank you very much, Ms. Smith.

Now, we will hear from Dr. Khachaturian. Dr. Khachaturian.

STATEMENT OF DR. ZAVEN KHACHATURIAN, CHIEF, PHYSIOLOGY OF AGING BRANCH, NATIONAL INSTITUTE ON AGING

Dr. KHACHATURIAN. Mr. Chairman, I speak as a representative of the National Institute on Aging, the Federal agency with the prime responsibility for conducting and supporting research on the biomedical and behavioral processes of aging and the diseases of the aged.

I have a written statement I would like to ask your permission to insert into the record.

Mr. CROCKETT. It will be inserted into the record.

Dr. KHACHATURIAN. I would just make some additional comments, and for brevity I will just summarize my statement.

During the past several years, I have been responsible for developing the Alzheimer's Disease Research Program at NIA, and the Alzheimer's Disease Research Center's program. And I would be speaking from that perspective.

Among the many debilitating conditions of the aged, Alzheimer's disease is the most devastating one. It is an area of high priority for the Department of Health and Human Services, Public Health Service, and in particular to the National Institute on Aging.

Now Alzheimer's disease and related activities at NIA take approximately 25 percent of NIA's resources. It is the single most important program and the largest program within the NIA's extramural programs.

Support for Alzheimer's disease within the Department of Health and Human Services has grown from nearly $4 million in 1976 to nearly $47 million in 1986.

In that period, we have made remarkable progress. We have moved from near ignorance to a point of promising hope and perhaps finding the cause and possibly treatment of Alzheimer's disease.

Yet, Alzheimer's disease remains a puzzle, a complex set of problems with many facets. Alzheimer's disease is many things to many people. At the same time, it is psychological stress to family members, it's a social burden to the family members, it's an economic disaster, it's a medical problem and a scientific challenge.

At this hearing, I will address the scientific achievements and windows of opportunities. However, the scientific issues cannot and must not be viewed in isolation from other equally important and equally urgent and compelling issues that are under consideration for public policy.

I'm talking about issues such as reimbursement, finance insurance, quality of care, type of care, service facilities, public education, legal and ethical issues, the need for data banks, and of course, the need for new knowledge.

Mr. Chairman, I want to make a few points.

First, scientific and medical issues are intricately related to other major public policy issues. For example, the search for diagnostic issues, that is, the search for finding out how to detect the disease, is a research issue. At the same time, it has a major implication for

public policy in regards to reimbursement, type of facility that the patient would be placed in, how the patient would be treated.

Therefore, one cannot look at one without looking at the other.

The same way, when one wants to find out the causes for the disease, it has tremendous implications for reimbursement and financing, so these issues—scientific issues and public policy issues—cannot be viewed in isolation. They are intricately tied together.

We must address the scientific issues in conjunction with these other issues that I've mentioned. During the last 10 years, rapid progress was made in this area, and I briefly want to identify some of these areas in which we've made tremendous progress.

One, we have learned that in this disease, there is a fundamental problem in the ability of nerve cells to talk to each other. There's a chemical deficit. There are many chemicals involved and we found out that this system is gone. We've learned that there are specific areas in the brain where specific cells die. We've found that out.

We're trying to find out what causes these cells to die. We found that there are abnormal proteins within the brain. We're trying to find out how these proteins are formed, what leads to their formation, and what we can do to prevent them.

We found out that there are vascular changes in the brain. This is essential for the functioning of the brain because it relies on energy and oxygen. With this system gone, the cells die.

We found out that there are some very fundamental metabolic changes which perhaps explain and account for some of the other changes that we have seen. There is some recent evidence that the disease involves more than the brain; that it might be a systemic disorder.

There are other types of cells involved; there are other types of activity involved in other organ systems. The possibility that genetic factors are involved is another major breakthrough. We found that there are certain factors that lead to a greater risk to getting Alzheimer's disease.

Three areas have been identified: one has to do with head trauma; genetics, as I mentioned, and aging are important risk factors. We found that there are certain toxins and infectious agents involved in the causation of the disease. We are trying to find out how these agents act; how we get them; how we can prevent them.

In the realm of diagnosis, tremendous strides have been made in improving neuropsychological assessment techniques. There are some new brain scanning devices that enable us to look at metabolic changes in the brain; there are devices for looking at chemical changes in the brain, and more recently some technological advances have enabled us to look at structural changes in the brain.

In the area of treatment, work is being done with various agents that possibly could slow down the progress of the disease or reverse it.

In the realm of management, the work is underway to reduce the confusion of the patients in facilities, to improve the management of the patients, and to reduce the burden of the family members.

Although progress has been made, there remain many windows of scientific opportunities. Progress in any area of science requires four essential ingredients: one has to do with ideas; the other one

has to do with people. The third area has to do with tools, scientific tools, and the fourth area has to do with resources.

We have three of the four of these areas now. In order to use our talents and resources more efficiently, recently we have established 10 Alzheimer's disease research centers throughout the country. These centers are designed to accomplish several goals.

One has to do with research; the other one has to do with teaching and training, another one education and information. Eventually, these centers will serve as places where care treatment and diagnostic activities can be conducted. Primarily, however, they are intended to be local, regional, and national resources.

The centers are the flagships of research armada we have set to sail against the battle of Alzheimer's disease. They are the very best we have in our country. They are designed to give visibility to Alzheimer's disease and coordinate work in a somewhat similar manner to the Manhattan project, although not the same scale, perhaps a lot similar to the space effort.

We certainly have the challenge. The challenge is not any less than any of these other goals. The importance of the problem is not any less than these other goals that we have. Clearly the excitement of achieving these goals is not any less than these other goals.

The Alzheimer's disease centers have already begun to achieve some of these goals. But we have a long way to go. The goals of the Alzheimer's Disease Research Centers are to create a coordinated research and diagnostic effort. They have begun working together; they are beginning to establish criteria and work in an coordinated manner to develop standardized instruments together. They are beginning to share ideas and resources together at the 10 centers.

They are also beginning to serve as a national resource, by sharing tissue material and information on patients. In addition, they have begun to serve as magnets for the private sector. We have three examples of this. Recently, at Duke University, a private benefactor gave the Duke Center $10 million, in addition to the amount that the Federal Government had given for Alzheimer's disease.

Similar private benefactors are beginning to join the battle and work with the Federal Government in supporting research in this area.

In another arena, we have begun to establish a patient register. This effort will serve as a national data resource for epidemiological data, for data on costs of patient care, data on types of facilities that are needed, and what's being utilized. Eventually, we hope this patient registry will set the stage for clinical trials.

Mr. Chairman, I want to close my remarks on a positive note of optimism. As one who has been inextricably involved in mobilizing the national research effort on Alzheimer's disease, I'm confident that finding the cause, and finding a treatment is within our grasp. We have the manpower, the talents, and the know-how in this country; we just need the national resolve to continue this effort.

Thank you.

[The prepared statement of Dr. Khachaturian follows:]

PREPARED STATEMENT OF ZAVEN KHACHATURIAN, PHD.

Mr. Chairman, I speak as a representative of the National Institute on Aging (NIA), the Federal agency with the prime responsibility for conducting and supporting research on the biomedical and behavioral processes of aging and the diseases of aging. Since its inception in 1974, the Institute has targeted Alzheimer's disease (AD) as one of its most important research priorities and challenges. Within the Public Health Service (PHS) of the Department of Health and Human Services (HHS), the NIA shares an interest and responsibility for this research with its sister institutes, the National Institute of Neurological and Communicative Disorders and Stroke and the National Institute of Allergy and Infectious Diseases; and the National Institute of Mental Health.

Among the many debilitating disorders of old age, the most frustrating include those that lead to a partial or complete loss in cognitive functioning. Alzheimer's disease is one of the most persistent and devastating dementing disorders of old age, eventually leading to a complete loss of memory and ability to learn. Alzheimer's disease presents enormous problems to the families of victims and raises complex social and economic issues for the public. At the same time, the disease offers unusual scientific challenges.

Alzheimer's disease is no longer regarded as a natural consequence of aging, as it was only a few years ago. It affects a substantial proportion of the aged, although the exact number of people affected is not known because of the difficulties involved in accurate diagnosis. Many of the families of AD patients are now well organized to provide support and share information. The general public is better informed about the disease through the efforts of the media. Congress and the Federal Government have begun to formulate public policy concerning services and research, and several agencies within the PHS have designated AD as a high-priority public health issue. A growing number of scientists have begun to study a broad spectrum of problems associated with the disease. In a relatively short period we have learned a considerable amount, but AD today still presents some challenging scientific opportunities for neuroscience. In the following account, I will attempt to provide an overview of the magnitude of the problem presented by AD and the remarkable scientific achievements that have already been made.

The number and proportion of elderly in the United States are rapidly increasing and are already having profound influences on American economic,

social, and political thinking and behavior. Biomedical research and its applied technologies have made it possible for an increasing number of people to survive until their 70s or 80s. Perhaps the most significant impact will prove to be economic: the costs of needed health care, clinical medicine, and biomedical research. Persons aged 65 years and older are at greatest risk for disease and, consequently, have the greatest need for medical services. Many age-related disabilities tend to be chronic, rather than acute, requiring long-term care. Such care is expensive, and the costs are expected to rise at rapidly due to increased numbers of elderly. Long-term care costs of AD patients and other aged persons will be considered in the Department's on going study of catastropic illness due to the President by the end of the year.

The following are some of the most dramatic demographic changes of this century. 1) The number of people over 65 years has risen from 3 million in 1900 to 27 million today and is projected to reach 43 million by 2020. At the same time, the proportion of those over 65 has risen from 4.1 percent in 1900 to 11 percent in 1980. 2) The greatest increases are among those over age 85 years who are likely to require special care. This segment of the population is expected to grow rapidly over the next 15 years and to reach over 5 million by 2000. 3) Although nearly 68 percent of older people consider themselves healthy and 90 percent live independently, nearly 86 percent have one or more chronic health conditions or disabilities. 4) The elderly account for 15 percent of all visits to physicians, 34 percent of all days spent in short-stay hospitals, 89 percent of all nursing home occupancy, and 29 percent of all money spent on personal health care. In 1984, the total cost of health care services to the elderly reached $120 billion.

Among the many age-related disabilities, those related to changes in the central nervous system or brain functioning have important implications for both public policy relating to health care services and national priorities for biomedical research. Failure in cognitive functioning is one of the principal indicators for institutionalization of the elderly in long-term care facilities. Long-term custodial care in an institutional setting is extremely expensive, often impersonal, and can contribute to further deterioration of health.

Approximately 10 percent of the elderly population show clinically significant

cognitive deficits. The frequency of intellectual impairment is considerably higher among those living in nursing homes, where an estimated 50 percent or more have some form of mental impairment. A significant number of these are now recognized to have AD. In 1984, the annual national expenditure for nursing home care was approximately $32 billion (Health Care Financing Review, Fall, 1985). It is estimated that during the next 10 years this expenditure will become a staggering $80 billion in constant dollars. The current estimated direct costs for AD alone, including nursing home care, is $38 billion per year. This, also, will grow over the next 10 years.

An important issue associated with AD is that of accurate diagnosis. There are as yet no specific studies identifying the frequency and cause of reversible cognitive impairments in the elderly, but it is estimated that up to 20 percent of persons aged 65 and over who have been labeled "demented" have reversible brain disorders that require evaluation and treatment. Misdiagnosis is extremely costly and a tragic waste when it leads to long-term institutionalization. There is clearly an urgent need to continue the quest for scientific knowledge concerning diagnosis and treatment possibilities for dementia and the biological mechanisms of aging and of such dementing disorders as AD.

The dimensions of the health problems posed by age-related changes in the central nervous system are vast. Basic research into the neurobiology of aging as the route to resolving these problems has been demonstrably successful in advancing knowledge of the human brain and providing the first real insights into some of the more baffling neurological disorders. The treatment of Parkinson's disease patients with L-dopa to replace the loss of a vital brain chemical, dopamine, and the discovery of the enkephalins and endorphins--the brain's own "opiate" drugs--are important examples.

These advances have come about because of a critical combination of talent and technology in neuroscience. It is now possible to obtain a detailed picture of what happens at the molecular level of a nerve cell as well as a clearer idea of how large clusters of nerve cells and systems operate in elaborating complex human behaviors. Enthusiasm in the field of neuroscience is running high, and researchers are optimistic about the future of brain research. In several areas of investigation, convergent approaches are focusing on key issues of neurobiology. In order to move toward the fundamental goal of prevention of

nervous system disorders, develop effective treatments for those presently afflicted, and ensure the rapid transfer of research advances to clinical applications, it is essential to capitalize on this new momentum in neuroscience. Progress in biological science needs good ideas, appropriate biological models, and the necessary technology--the methods and tools to make the observations fruitful. The neurosciences can now command all three of these elements. There has never been a lack of good ideas or experimental models, but only in the past 20 or 30 years have there been significant gains in technological progress. These achievements in technology are expected to continue making a substantial difference in the rate of advancement of neuroscientific knowledge.

Although systematic studies of age-related changes in the human brain have a 100-year history, strong interest in this subject is recent. During the last decade a growing community of neuroscientists, spurred partly by the availability of Federal funds for research, has begun to study a broad range of topics in the neurobiology of aging. These range from basic molecular to clinical issues, and from the physical chemistry of membrane transport mechanisms to the neuropsychiatric assessment of the aging brain. Not long ago, little was known about "senility," and AD was considered a hopeless affliction of the aged. Now we know that chemical and physical changes in the brain can account for some of the memory deficits in AD and the benign forgetfulness of the aged. The remarkable pace of scientific progress in this area of research increases the likelihood that some forms of dementia will be treatable by pharmacological agents.

Research supported by the PHS has also made it possible to start formulating a coherent scientific story on the pathogenesis of AD and to identify a number of exciting scientific opportunities that are ready to be exploited. Of even greater importance is that it is now possible to propose testable hypotheses that can provide a framework for interrelating some of the observations reported by scientists working in this area of research.

During the past few years, it has been clearly established that the hallmark of AD is a serious defect in the cholinergic system (one of the many chemicals used by nerve cells for cell to cell communcation). This finding has stimulated considerable scientific activity aimed at identifying the exact nature of this

neurochemical defect and finding a pharmacological means of ameliorating the disease. This type of research has been driven by the assumption that the neurochemical deficits in AD result primarily from biochemical abnormalities in the synthesis or release of the neurotransmitter acetylcholine; it is assumed that the affected brain cells would function normally if these biochemical abnormalities could be corrected. Thus, the search for treatment has focused on pharmacological manipulations aimed at 1) increasing the supply of the substrate necessary for the synthesis of the neurotransmitter, 2) increasing the amount of the neurotransmitter released, 3) prolonging the availability of the neurotransmitter at the synaptic junction by blocking its breakdown, and 4) manipulating the sensitivity of receptors at the postsynaptic membrane.

Despite some promising initial results in treatment of AD with agents such as choline, lecithin, and physostigmine, this effort in choinergic pharmacology has not produced any consistent or long-lasting treatment for AD. Several theories attempt to explain this lack of success. First, it is unlikely that AD results from a deficit in a single neurotransmitter system. There is mounting evidence that multiple neurotransmitter systems and neuropeptides are involved. Second, the observed neurochemical changes in AD might be epiphenomena associated with or a consequence of cell death. In AD cell death occurs in specific regions of the brain, particularly in areas richly innervated with cholinergic cells. Third, the neurochemical deficits might be a consequence of other changes within the cell, such as abnormal oxidative or glucose metabolism.

Investigators have yet to determine why brain cells die in AD and whether or not such cell death can be averted by pharmacological means. There are several working hypotheses concerning the possible mechanisms of cell death. One of the most active areas of study focuses on the chemistry of neurofibrillary tangles within nerve cells that are the classic pathological markers of AD. It is now known that these filaments are composed of highly insoluble protein formed by a cross-linking reaction. These insoluble protein masses might form a physical blockage that interferes with axoplasmic transport mechanisms, thus leading to cell death. It is essential that future research focus on the biochemistry of protein cross-linking reactions and the enzymology of such reactions.

Another important area of study concerns the role of modulators (chemicals that modify the effects of a neurotransmitter) and neurotrophic factors affecting the functioning and viability of cells. There is some evidence that the function

and viability of the nerve cell is compromised when there is no chemical feedback or neurotrophic factor from a target cell. The role of neuropeptides such as somatostatin and the mechanisms by which they modulate neuronal activity are not well understood. Whether or not such neuromodulators also serve as trophic factors is not known. The chemistry of neuromodulators and the neurotrophic factors is an area that needs greater emphasis.

A third area of needed study concerns the biochemistry of metabolism within the cytosol, especially oxidative metabolism and glucose utilization. It is important to have a better understanding of changes in such metabolic pathways associated with aging and disease states.

A fourth cluster of essential studies looks at membrane biophysics and how membrane changes influence transport and homeostasis of essential ions such as calcium. There is some evidence that aging, as well as certain diseases, causes changes in the transport mechanisms that regulate cytosol-free calcium concentration. We need to learn more about the biophysics of ion channels, pumps, and transport systems associated with cell and organelle membranes. Finally, we need to know more about such environmental toxins as aluminum and infectious agents such as the slow-acting viruses or virus-like particles that have been associated with cell death in AD. The chemistry of how such agents interfere with cell functioning is still not well understood. Also, we do not know why there appears to be selective vulnerability; the role of genetic factors in such selectivity is an area needing greater study.

All of these results are extremely important, because they provide a crucial beginning for piecing together the AD puzzle. It is now possible to formulate testable hypotheses that can provide a common framework for interrelating a number of the discrete findings discussed here. For example, in study after study we are seeing the importance of calcium levels within the cell in terms of cell-to-cell communication and even the viability of the cell itself. Time after time, findings in AD brains point to a disruption in the delicately balanced homeostatic system of transporting calcium across the cell membrane. Such a disruption of the system could be a consequence of exposure to a neurotoxin, such as aluminum, pathogenic agents involving either genes or infectious agents, other insults, or even aging. Further study should allow us to develop integrated theories of aging and better understand the biological mechanism of diseases such as AD.

In summary, the systematic study of AD was begun only within the last decade, despite the fact that the disease was first described nearly three-quarters of a century ago. In this brief period of time, our knowledge of this disease has advanced from nearly total ignorance to a level at which it is possible to begin testing potential treatments and to formulate viable hypotheses to explain its causes.

The scientific community now has the tools, the knowledge base, and the means to solve the problem of AD within the next decade. This remarkable progress in dementia research has been made because the availability of scientific knowledge, technology, and methods--the bricks and mortar to start building a structure--has been more than equalled by increased interest and enthusiasm in the medical community and among the general public.

The PHS, of which the National Institute on Aging is a part, has supported a significant portion of basic biomedical research in this country during the last 30 years. A tremendous amount of this work has had direct and indirect bearing on our understanding of the basic mechanism of cell function, including that of neurons. Using knowledge gained from such areas of science as biochemistry, cellular and molecular biology, bioengineering, physics, genetics, recombinant DNA, and cloning technology, it is now feasible to make rapid progress in understanding the cause or causes of AD as well as other disabling disorders of the aged.

There is no reason to doubt that progress and scientific achievements will be any less spectacular during the next few years as they have been recently, provided that we are able and willing to maintain the enthusiasm of the scientific community and provide the necessary resources. The challenges of understanding AD and finding a cure will require national resolve to maintain the momentum we have begun.

Thank you for this opportunity to speak with you about Alzheimer's disease. I will be pleased to answer any questions you may have.

Mr. CROCKETT. Don't you also have a national resolve, and all you need is a national budget that would permit you to do it?

Thank you, very much, Dr. Khachaturian.

Mr. CONYERS. Well, what's the answer?

Mr. KHACHATURIAN. What was the question?

Mr. CROCKETT. He wants to reserve the answer until we get to the question period.

Now, the next witness is Mr. Tom Crook, who is president of the Memory Assessment Clinic.

Welcome, Mr. Crook. You may proceed.

Mr. CROOK. Thank you, Mr. Chairman.

STATEMENT OF TOM CROOK, PRESIDENT, MEMORY ASSESSMENT CLINIC

Mr. CROOK. Thank you, Mr. Chairman, Mr. Conyers, and Mr. Hertel.

It's a privilege to be here this morning to address the Select Committee on Aging and Mr. Conyers.

It's certainly clear to members of the committee that Alzheimer's disease poses a major challenge to the American health-care system, and a personal tragedy of immeasurable proportions to its victims and members of their families.

One of the critical questions we have to ask is, basically, How can the suffering of Alzheimer's patients and their families be minimized? How can we hasten the discovery of an effective means of treating or preventing the disorder?

Clearly, both the Federal and State Governments can play important roles in addressing both of these questions. Now, my personal perspective on what these roles might be comes from my own experience in administering the National Institute of Mental Health Program to discover effective drug treatments, and now serving as an investigator looking for effective treatments and as a clinician consulted daily by many patients concerned about Alzheimer's disease.

Now, the current plight of persons seeking diagnostic and treatment services has been eloquently described and well documented before this committee.

Briefly, expert and comprehensive diagnostic services are frequently unavailable; few resources are available to families attempting to manage the disorder within the home; and institutionalization may present overwhelming problems for both the patient and family.

In my view, this situation need not exist. A cure for Alzheimer's disease is not yet at hand, but the disorder can certainly be managed better than is now the case.

A key to more effectively treating Alzheimer's disease and reducing the burden on the family may lie, in my view, in the establishment of geographically dispersed treatment research centers around the United States. Such sites would allow investigators to evaluate different treatment strategies and develop optimal approaches for managing different stages of the disorder.

Research at these sites would differ substantially from that at the existing centers as described by Dr. Khachaturian, in that the

primary focus would be on service delivery treatment and research, whereas the primary focus in existing centers is on basic neuroscience research.

Treatment centers would provide comprehensive state-of-the-art diagnostic and treatment services and would include facilities for adult day care, short term respite stays, and long term care. Studies conducted at these sites would focus on methods and strategies for minimizing the behaviorial, emotional, and financial consequences of Alzheimer's disease.

Particular emphasis would be placed on identifying cost-effective methods for assisting the family in maintaining Alzheimer's disease patients in the community. Studies would also be undertaken to access the efficacy of experimental treatments for Alzheimer's disease.

Now, some of these provisions were of course contained in Mr. Pepper's proposed legislation, H.R. 524.

Now, among the specific issues that in my mind need to be addressed and could be addressed at these centers, are the following:

No. 1, development of improved, cost-effective diagnostic procedures.

No. 2, developing optimal behavioral and pharmacologic strategies for treating the behavioral consequences of Alzheimer's disease and the frequent secondary symptoms, such as depression and sleep disorders, and other things that exist and can in fact be managed reasonably well.

No. 3, developing innovative experimental programs to assist family members in managing Alzheimer's disease patients outside the institution.

No. 4, evaluating experimental drugs and other techniques for treating Alzheimer's disease.

No. 5, establishing the role of respite, both in and outside the home, and day care in easing the burden of families in delaying or preventing hospitalization.

No. 6, establishing the role of family support groups and reducing family stress and delaying and preventing institutionalization. Of course, this would be undertaken in cooperation with the Alzheimer's Disease and Related Disorders Association.

No. 7, developing optimal strategies for treating depression and other disorders frequently seen in family members.

And, last, developing optimal environments for managing Alzheimer's disease within both the home and within institutions.

In addition to serving as centers for treatment and research, the proposed sites could function as regional centers for patient information and referral. Health care providers with expertise in Alzheimer's disease and appropriate treatment facilities within the region would be identified as sources for referral. Thus, patients and family members would have a single source to which they could turn for comprehensive information on the resources available to them for treating the disorder.

Treatment research sites could also be expected to serve important educational and training functions within the regions they serve. The results of the research would be expected to be translated, as soon as possible, into practical programs within the region.

Beyond that, seminars, training sessions, and on-site clinical training for physicians and others in the community could be provided.

Now, within the current realities of Gramm-Rudman, it seems to me that 5 to 10 such programs at perhaps a yearly cost of $1 million each, could have an immediate and significant national impact on the treatment of Alzheimer's disease. If these research sites are even modestly successful in identifying better strategies and methods for preventing institutionalization, the return on investment in my mind would be remarkable.

And we talk about not spending additional money but saving money now, it's important in that light to consider that the Library of Congress, as members of the committee are aware, has proposed that the bill for nursing home care in 1990 would be $67 billion annually.

Beyond this immediate question is the second question, that is, the future: beyond managing the very unfortunate situation we have today, how can we develop an effective means of preventing or treating Alzheimer's disease?

At the National Institute of Mental Health, as well as the National Institute on Aging and National Institute of Neurology, Communicative Disorders and Stroke, and other Federal agencies, there are active programs underway to develop effective treatments.

Now, these studies have been extremely productive in recent years. While we do not have an effective treatment, we do have a vastly better idea than we had a few years ago of what the neurochemical problems are that underlie Alzheimer's disease, and we can in fact produce small changes in the disorder. These changes are not of immediate clinical significance, but they are certainly extremely promising in terms of developing effective treatments in the future.

Quite simply, increased Federal spending to support this treatment research will hasten the day when we have an effective treatment for the disorder or a means of preventing it. Beyond the question of Federal funding itself is the question of the role the Federal Government plays in encouraging investment on the part of the private sector, and this is particularly important with regard to the question of drug treatment.

The Food and Drug Administration of the United States, of course, is seen as the organization within the Federal Government which sets the rules under which drug research is conducted. To the extent that these rules are clear and understood by the pharmaceutical industry, private investment will be encouraged. To my mind, the FDA has done quite a good job, recently, and we are seeing major investment on the part of pharmaceutical companies in this area. This investment I think should not be minimized and could assist greatly in the search for an effective cure.

Finally, it seems to me that the Congress, in addition to allocating funds directly to Alzheimer's research and encouraging investment from the private sector, that is, by insuring that the rules are clear under which the research is conducted, can encourage work among organizations or agencies within the Government.

An example of that is a committee that I sat on during previous years representing the National Institute of Mental Health that

came about because of legislation in the NASA funding which says, basically, that some space research should be used on problems here on Earth.

We met repeatedly with members of NASA and the question was, how can this wonderful space technology be used to solve some of the serious problems we now have in Alzheimer's disease. As a result of that, several things have been developed. At the moment, monitoring devices, for example, are being developed that will assist family members dealing with problems like nighttime wandering. Particular pumps are being developed as well that will allow drugs to be infused directly into the brain, thereby assisting research.

I haven't figured out exactly how the B-1 legislation could be used to the advantage of Alzheimer's disease, but I do think a lot goes on within the Federal Government within different agencies that could in fact be brought to bear on this important question of developing treatments or better managing Alzheimer's disease.

In summary, may I suggest that the Federal agenda for Alzheimer's disease include both an immediate attempt to improve the treatment of the disorder and thus relieve the overwhelming burden on patients and members of their families, and a longer range effort to find an effective means of preventing or treating this tragic and dehumanizing disorder.

Thank you, Mr. Chairman.

Mr. CROCKETT. Thank you, very much, Mr. Crook. I'm wondering, and either one of you should feel at liberty to comment on this, but I'm really addressing it to Dr. Khachaturian. Isn't there a basic, philosophical question here with respect to the relationship between the Federal Government and the states in terms of doing something about doing more about Alzheimer's disease.

There seems to be a feeling on the part of the current administration in Washington, that the area of Federal concern should be limited to national defense and foreign affairs, and we should back off from as many of the so-called social programs as possible. We should starve them out and leave it to the States to take care of that.

Now, that was the governmental philosophy certainly prior to the New Deal, and then beginning with the New Deal, we became concerned with health problems. Infantile paralysis is a good example of that. We became concerned with problems of education and so forth.

I'm thinking about your point that we need more Federal aid to the area of research, and I'm also thinking about Ms. Smith's point that we need more Federal aid in the area of assisting the victims as well as family support for Alzheimer's. Now, there's a basic inconsistency there, as I see it. In the past, and the present administration seems to be coming back to it, it was the function of the State and the State budget to raise the money for problems such as this. At most, the Federal Government was expected to take care of the research.

Do you have any comments on that?

Mr. KHACHATURIAN. It goes beyond my competence to get into that issue. What I was trying to say, Mr. Chairman, is that the issue is really research and services are intricately related. That

we should look at it as an integrated totality. That what we do in research will have an impact on services and that when we are thinking about our research priorities, it should be with the service needs and the needs of the family members in mind, and I gave the example of diagnosis as being one. But there are many others.

Mr. CROCKETT. You mentioned that we have 12 centers today, is that right?

Mr. KHACHATURIAN. Ten centers.

Mr. CROCKETT. The Pepper bill would appropriate money to create 20 centers?

Mr. KHACHATURIAN. That's right.

Mr. CROCKETT. Is that the recommendation of the National Health Institutes?

Mr. KHACHATURIAN. The centers that we have right now can perform some of the functions that Mr. Pepper's centers would also propose to perform.

Mr. CROCKETT. But your centers now are not treatment centers, are they? Aren't they basically research centers?

Mr. KHACHATURIAN. They are research centers, but in the process of doing research, they also provide treatment to patients, because they are looking at patients and patients do come there for evaluation. And they do come from many regions.

They are not designated as treatment centers but they do provide treatment, to the extent that treatments are available.

Mr. CROCKETT. Yes. Thank you.

Mr. Conyers.

Mr. CONYERS. Mr. Chairman, I see Representative Hollister.

Mr. CROCKETT. We'll come back to Representative Hollister's presentation.

Mr. CONYERS. OK.

Mr. CROCKETT. Unless you wish to defer your questions until after you've heard his presentation?

Mr. CONYERS. Yes; and then I can get the panel all at once.

Mr. CROCKETT. Then we'll hear from Representative Hollister of the Michigan House of Representatives.

Mr. HOLLISTER. Thank you, Mr. Chairman.

STATEMENT OF DAVID HOLLISTER, CHAIRMAN, APPROPRIATIONS SUBCOMMITTEE ON SOCIAL SERVICES, MICHIGAN STATE LEGISLATURE

Mr. HOLLISTER. I apologize for being late. I was testifying at a hearing next door on a bill that I'm sponsoring on high risk 4-year-olds, the other end of the continuum, and trying to develop a State program for high-risk 4-year-olds.

And I also chair a special committee in the legislature on aging and have chaired it for a number of years. I chair the welfare budget and have responsibility for the Medicaid budget, so I come at this from a number of different perspectives, and hope that I can offer some help to you here.

I spent a lot of time trying to understand health care issues, and recently participated in a panel with 24 top legislators who deal with health care—not top, let's say senior, like myself—legislators who deal with health care issues across the country. And Gail Wa-

lenski, who's a top researcher in the country, said name the five most important critical issues facing legislators and policymakers in the area of health care.

And we talked about AIDS, transplants, uncompensated care—we had a whole bunch of issues—and after we listed them all, liability insurance, malpractice, issues that we were all thinking about, she said you are absolutely wrong.

The single most important issue facing health care policymakers, legislators, and Congressmen is the aging population, those over 75 and growing four times the rate of the national average. And as legislators who have responsibility for the Medicaid budget, it's something we have to be thinking about. And it just simply knocked their socks off. It's something we really hadn't been thinking about because we are organized to think about the immediate problems, and not that aging population, and the tidal wave that it is creating for us.

And as we thought about that tidal wave, and as I think about the Michigan Medicaid budget, there are a couple of things I just want to share with you.

In our Medicaid budget, one-third of the people, one-third of the clients on our welfare budget, spend two-thirds of the dollars. The idea that a welfare mother with two children is spending all of our money is absolutely wrong. That one-third of the population, which is the aged, the blind, and disabled, is spending two-thirds of our Medicaid dollars, and they are spending two-thirds of those in the last 6 months of their life.

And that's important for us to understand. That was one of the implications that came to mind immediately. I had a hearing this week in the Joint Committee on Aging, and our region four director testified that 60 percent of the people they see in the community mental health system are women. And 40 percent of them are there as a consequence of caring for elderly parents.

We are shifting responsibilities to the vulnerable or poor people who don't have the resources to deal with them. Alzheimer's is one of those hidden issues that lies below the surface in these numbers that we are looking at, this tidal wave of those over 75 that are growing at four times the rate of the rest of the population.

Michigan has a very sophisticated Medicaid Program; we are proud of it. It's one of the finest in the country and we spend almost $2 billion on it. And during the recession, we made 57 changes of policy to try and keep the cost down, so we're very cost conscious. We share some of your concerns as far as deficit and trying to deal with that. So we know that we have to take initiatives that are cost effective.

And we've done a pretty good job. The 10 industrial States, largest States, their Medicaid budgets grow at a rate of 20 percent a year. The surrounding States of Ohio, Illinois, Wisconsin, Minnesota, they grow at 15 percent a year for Medicaid budgets. Ours is growing at 12.5 percent. So we have tried to slow the rate of growth, and we've done that primarily by some very disciplined health care policy.

We have a very sophisticated health planning network. I hope you don't repeal the Health Planning Act. We have a very sophisticated certificate of need process. I hope you don't follow the Presi-

dent's recommendation and gut that. We have a debedding, we're trying to get some of the beds off line that have been identified as excess, and we have a very elaborate continuum of care.

Because we have this elaborate continuum of care, in Michigan we spend 20 cents of our Medicaid dollar on nursing homes. Indiana spends 55 cents out of its Medicaid dollars on nursing homes. What that means is, if your elderly parent becomes ill in Indiana, they go to a nursing home and they die. In Michigan, they stay at home and they have a visiting nurse; they have church services, they have home health care, they have a continuum that supports them.

Now, that's both cost effective and it is more appropriate care, and it's where most people want to be cared for, so it's a more appropriate setting. The dollars that are needed to support that continuum are being shrunk. And I worry about that. It's one of the terrible dilemmas we have and as I've talked to the communities on dealing with Alzheimer's and dealing with this continuum of over 75, without question, the No. 1 recommendation is more in-home services, more respite care, more creative ideas.

One of the ideas that Indiana did try is to maintain empty beds. When a person is in a long-term-care facility, a nursing home or whatever it is, and they develop an illness, and they are taken to the hospital for a number of days, and there's pressure to fill that bed by the industry, then the person has no place to go.

And one of the ideas is to buy that bed or pay half of the Medicaid rate or some rate, so that the nursing home isn't losing completely, but to keep the bed there for the person to come back to. Michigan's Medicaid proposal this year is to do the same thing, but to take that empty bed during that period of hospitalization, and use it for respite care for the families who have seniors at home.

So we're trying to get double social utility. We're protecting the industry, and their investment, and keeping that bed paid for, but give some respite care in the meantime, because respite care is one of the critical issues you find as you deal with Alzheimer's and other issues of the elderly.

I apologize for being late, I'm here to primarily answer your questions but to share with you our growing concern for this aging population, which is a tidal wave that's coming at us, and which has massive implications for legislators because of our Medicaid responsibility. We have to be creative; we have been creative in Michigan, but the Federal budget cuts that are coming at us are going to make our effort that much harder. We'll be as creative as we can, and we look forward to a partnership as we try and wrestle with how to solve some of these very complex human problems that all of us face.

Mr. CROCKETT. Thank you very much, Mr. Hollister.

Mr. Conyers.

Mr. CONYERS. Thank you. Representative Hollister, would you describe the relationship between the Federal Government and the State government in funding health programs for the State and county and the block grant programs?

Mr. HOLLISTER. Would I describe it?

Mr. CONYERS. Yes.

Mr. HOLLISTER. In terms of the last 5 years?

Mr. CONYERS. No; as of right now.

Mr. HOLLISTER. Well, if you will excuse the expression, I call it the shift in the shaft.

Mr. CONYERS. I'll excuse the expression. Now, tell me about that.

Mr. HOLLISTER. How that works. I used to teach high school and you got to get right down to the bottom line, and that is that as you shift responsibility from the Federal to the State level, you take away the resources and our ability to respond. And we can do a lot of things, and we can do them fairly creatively if we have the resources. But as we are getting more and more responsibility, we have less and less resources.

Local communities right now are thinking about raising the tax level just to try and make up for the losses that are coming, and then the tax reform proposal takes away the ability to have municipal free bonds, and that concerns them.

Then we turn to revenue sharing. In this community, revenue sharing means that on October 1, Detroit has to layoff 700 policemen. Now, that's an awful lot of people, whereas in my community the loss of revenue sharing means 30 policemen. That's how we have chosen in Michigan: 90 percent of all those revenue-sharing dollars in Michigan go for police and fire protection.

And that's massive losses, and these local communities are trying to figure out ways to make up for that. Local communities have two choices. If they want to keep policemen they've got to layoff health nurses. They've got to cut back on the parks; they've got to not fix the roads. Or they're going to raise taxes. And my mayor, locally, in Lansing, proposed raising taxes about a week ago, and he's getting his comeuppance. I'm being kind here.

He's taking a beating because he proposed that we raise taxes. Detroit can't raise taxes. They're at their millage cap. They've got to go to a special election. I don't know if you can get a special tax increase in this community to make up for these losses.

And that's just one program. That's just revenue sharing. You take all the other programs—we estimate the loss in Michigan from the revenue-sharing loss, Gramm-Rudman, and whatever budget you pass, even if it's the President's original proposal, and we will lose on October 1, $600 million. Now $600 million, that's 10 percent of our budget, Congressman.

Mr. CONYERS. All right. Now we're getting down to some figures.

Mr. HOLLISTER. You know, $600 million is a lot of dollars. Our total general fund budget that we are dealing with right now is $5.9 billion, and we are going to lose $600 million Federal dollars on October 1. I chair the welfare budget and we take a big bite of that. It's going to be about $200 million right out of our budget.

We are trying to figure out now how to do more with less. And it gets real complicated, especially after we've been in this for 5 years of cuts.

Mr. CONYERS. OK. Well, what have you figured out?

Mr. HOLLISTER. I figured out that the military budget that you're looking at is obscene.

Mr. CONYERS. You didn't have to figure that out. I'm talking about what did you figure out about what you are going to do with delivering health care to Michigan, now that you know what's hap-

pening, and you've told us that you may lose as much or more than $600 million.

Mr. HOLLISTER. That's 10 percent of our budget, Congressman.

Mr. CONYERS. Yes. I understand that you are losing about 20 percent when the Gramm-Rudman cuts affect fiscal year 1987.

Mr. HOLLISTER. Yes.

Mr. CONYERS. Now, the question isn't how obscene the military budget is. We've batted the military budget around, he sits on the Armed Services Committee. The question I need to know as much as I can in this limited hearing is what is going to happen to all of these services you've described in the reality of the $600 million cut?

Mr. HOLLISTER. The reality is, Congressman, we are going to be doing some triage, and somebody's going overboard.

Mr. CONYERS. OK. Tell me more.

Mr. HOLLISTER. I'm waiting until after November to tell you.

Mr. CONYERS. Until after November?

Mr. HOLLISTER. Right.

Mr. CONYERS. Well, you know, sir, I'm glad you mentioned you are waiting until after the elections. You know, that presumes you are going to get reelected——

Mr. HOLLISTER. Right.

Mr. CONYERS [continuing]. First of all, doesn't it?

Mr. HOLLISTER. No.

Mr. CONYERS. Oh, it doesn't?

Mr. HOLLISTER. No, because——

Mr. CONYERS. Are you up for election this year?

Mr. HOLLISTER. Yes, I am, but let me tell you what happened. I was——

Mr. CONYERS. Well, then why——

Mr. HOLLISTER [continuing]. One of the 16 people that voted against the tax cut.

Mr. CONYERS. Well, then why—let me ask you this question. And I'm glad of that vote and I'm glad you inserted it into our discussion. Why do we have to wait until after people are elected and put back into office to find out what's going to happen to a $600 million cut? Would it not be wiser, sir, since you were one of the braver and more experienced State legislators, that we find out about who is going to be going overboard before November?

Mr. HOLLISTER. Congressman, I sent to every Member of the congressional delegation, to both House and Senate Members, an analysis of the budget cuts and how they impact Michigan. It's called Economic Update No. 7, and I don't know if you've gotten a chance to read it yet or not?

Mr. CONYERS. I've never seen or heard of it.

Mr. HOLLISTER. Then I would talk to your staff people about that, Congressman.

Mr. CONYERS. But why don't you just tell us—don't worry about my staff. Let's get the hearing here, and I mean, I can go back and read it, my staff can get it. But we've got a hearing in which all the people here I don't think are familiar with that.

I'm trying not to be hostile, OK, so let me just get the question, please.

I think it is a little coldblooded to talk about some people are going to be going overboard, but then we're going to figure out what we do and who is going overboard in November, after the elections.

I would like to know, since we are holding the hearing in April, whose going overboard, now?

Mr. HOLLISTER. OK.

Mr. CONYERS. If you can tell us that.

Mr. HOLLISTER. I can do that.

Mr. CONYERS. If you can't tell us, I'm not trying to force answers that you may not be prepared to give. I'm not trying to do that, so just answer the question, okay?

Mr. HOLLISTER. I'll be glad to. In the last 5 years, the Michigan legislature cut its budget by 20 percent. I served on the committee that made the decisions. I can tell you where the decisions were made and why we made them.

Mr. CONYERS. Well, tell me.

Mr. HOLLISTER. Two-thirds of all the money in the Michigan budget is in four programs.

Mr. CONYERS. Name them.

Mr. HOLLISTER. Higher education, our colleges and universities, and this is one of the finest ones we are in today, We cut this university and we cut all the other universities, and because we cut those universities, tuitions have gone up. There are consequences to the decisions we've made.

The next big budget is K-12 education, our kindergarten through 12th grade school districts. They were cut. And at one point, Congressman, five Michigan school districts closed during that last recession because people turned millages down.

When the Governor took office in January 1983, 40 school districts notified him that they would close before April 1, 40, and we had 5 close at that time. My parents live in Arizona and they called and said, Dave, what's going on in Michigan. Why are you closing your school districts?

What message does that send to the Nation? What message does that send to the economic development community that wants to come into Michigan when you close five school districts? I don't think you bring businesses into the community when you close up the schools. But that's what we did.

The next big budget is mental health. And we moved people out of our institutions, as you know. We are under court orders now. We didn't have the adequate staff so we overused drugs. We got a new illness called tardive dyskenesia, and we are also under court orders because of the inadequate staffing we have. We are not even back to where we were in 1979.

The next big budget is the department of social services. That budget's been cut every year for the last 5 years. Two-thirds of the people, Congressman, on welfare are children. Two-thirds of the people on welfare are children. That's where two-thirds of all the money is in the Michigan budget.

Higher education—and we support 97 colleges, community colleges and universities, and we used to be proud of that. I remember when we used to be proud of it. Now we're talking about closing it—K-12, mental health and SS; when we make 600 million dollars'

worth of cuts, two-thirds of the $600 million will come from those four programs.

Two-thirds of the cuts will come out of those four programs, and I'll be sitting on the committee, making those decisions. So, I'm not telling you what might happen; I'm telling you what actually did happen during the last recession and what I think will happen after next year.

I voted against the tax cut because I thought it was the wrong thing to do. I voted for the tax increase; I think it was one of the better things that I did as a legislator, so I'm not here to be a smart alec about it. But you have to make hard decisions.

Unfortunately, when the Michigan Legislature made those hard decisions, two senators were recalled. The Governor was under recall. Over a dozen legislators were under recall and in Michigan, it's very easy to recall. You get a petition to get on the ballot and the answer is yes or no, do you want to get this rascal out of there for voting taxes. That's the only question you have to vote on. Well, you know what that's going what the answer is going in. So, because of the tax revolt that there came out of that, there was not a lot of courage in the legislature to talk about the alternative. We don't have to make these cuts, Congressman.

The alternative is revenues. And I think the debate here is not a fiscal debate. It's an ethical debate. What is the legitimate role of Government and what are we willing to pay for it? And I'm willing to pay for these services because they're good services. I think we have one of the best university systems in the world. We have three world-class universities and you're at one of them today. Michigan State and the University of Michigan are the others.

I'm a graduate of Michigan State, and I've got two children at the University of Michigan, so I've had experience with all of them. I think we have the finest schools; I think we have the finest mental health system and we have an elaborate social services system, but it's being downsized because we are not willing to pay for them.

Mr. CONYERS. Well, is it not true, then, that there is a tax cut coming out that has already come out? What size is that cut?

Mr. HOLLISTER. The tax cut that we made was a roll back to the original 4.6; after we raised them, it rolled back automatically, and we simply accelerated the rollback. It was about $190 million.

Mr. CONYERS. $190 million.

Mr. HOLLISTER. The final.

Mr. CONYERS. So that in the face of all the Federal tax, the budget, Gramm-Rudman, we have instituted a State tax reduction?

Mr. HOLLISTER. It was already built in when we adopted the tax increase, it was an automatic phaseout over time, as the economy returned. And what happened was, that was accelerated, so instead of phasing it out over I think it's going to be 4 years, we phased it out over 3 years. And we did that because of the pressure of the Senate Republicans who got control of the legislature because of the tax revolt. So it became a very political partisan issue, unfortunately. Taxes should not be a partisan issue. It became one, unfortunately.

Mr. CONYERS. Well, I want to thank you because the chairman's indicating, and I didn't mean to get into time. We can't get to all of our private sector people.

Mr. HOLLISTER. I apologize. Right.

Mr. CROCKETT. Now, let's get back to Alzheimer's.

Mr. HOLLISTER. It's all related. All related.

Mr. CROCKETT. Congressman Hertel.

Mr. HERTEL. Well, Mr. Chairman, I first of all want to thank Girard for giving us again some insight to individual cases, and Dr. Smith. I haven't had a chance to read all of the testimony you put in the record, but appreciate your expertise and ideas. I thank all the witnesses on the panels that I've been able to hear testify today, on the cost problems for the families, and obviously the cost for the research. That is what we've been trying to emphasize in Washington through these discussions.

And I want to just say a word about my colleague, David Hollister, with whom I've had the honor to serve in the State legislature. No one really knows more about the problems that we face regarding social services.

There are others that on equal given days help him champion these causes, but that report that you did submit to us annually is very helpful; that breakdown and your courageous work in the areas of mental health even at the worst of times are greatly appreciated by the people in the State.

I also want to thank the people who came here today for all the hard work you do on a regular basis, and all the expertise that you provide us. It's good for our colleagues here today to hear this testimony first hand. And this kind of fire power gives us even a stronger argument to take back to all the people in the Congress.

Mr. CROCKETT. Now the fact that you haven't had any more questions than you have had is testimony to the fact that you made excellent presentations and anticipated most of our questions.

Are there any comments any other witnesses would like to make at this time?

[No response.]

Mr. CROCKETT. Well, our thanks to each of you for your presentation.

Now, we're going to allow a few of the remaining minutes to entertain comments from the people in the audience who might have a contribution to make. I would ask that you try and keep your comments to no longer than 2 minutes.

Is there anyone who would like to be recognized. I see a hand back here. Will you stand and give your name? You may need to come up and share a microphone over here.

If there are any others, I suggest that you just line up behind her, and we'll have your comments one right after the other.

Now, give your name, and then make your comment. If you are representing an organization, identify the organization.

STATEMENT OF HELEN DENT, FLINT, MI

Ms. DENT. Can everyone hear me? My name is Helen Dent. I live near Flint. I think it is imperative that I relate my findings to

bring assistance and help to everyone involved in this dishonorable and unwelcome dementia.

If I may relate this story, I have contacted people for 3 years to get help. I have contacted Claude Pepper; I have a letter from him here saying, "Your recent correspondence regarding your experience with your daughter and husband have been received and carefully noted. And of course I was very sorry to hear of your plight."

My husband has Alzheimer's disease, probably for 11 years. On July 16, 1983, our adult children, David and Carol, came home with their spouses and three grandchildren. They abducted my husband under the pretense of a vacation for a week or two.

They promised to bring him back. I have not seen him since, except in court three times. I have been to court 41 times myself. My life has been hell for 3 years. I've tried everywhere, Ronald Reagan, Nancy Reagan, I've tried everything to get help. No one has helped me.

On July 16, which was on a Saturday, they took my husband to a lawyer. A summons was already drawn up and they had him sign it for a divorce. We were married 49 years this June. My life has been hell, like I said. Where can I get help for my husband and I? It is deplorable. They've wiped us out of all our income and what are we supposed to be doing?

They've tried to take our house, our furniture, everything. They've wiped us out. The lawyers, I have six lawyers suing me. It's deplorable what they done to us. All because my husband has Alzheimer's disease; he does not know what he's doing. He doesn't recognize me anymore and our daughter was ruled in the court that she would take care of him. She said, I will take care of my dad. I want to take care of my dad. Just as soon as she didn't get $3,000 a month at her door, she's kicked him out and put him in a nursing home. It's costing us $2,000 a month to keep him.

I've tried to get guardian conservator, I couldn't. And now there isn't enough income for me to live. They've shut my electricity off; my phone off. That's it.

Mr. CROCKETT. Well, thank you very much. It's really a problem I think that should be addressed by the local officials in the Flint area, and I would strongly recommend that.

Let's hear the next comment.

Ms. DENT. I do have letters and I'd be glad to hand them out. Thank you very much. If anyone here can help my husband and I, it would be most welcome. The lawyers have wiped us out. Thank you, everyone.

Mr. CROCKETT. All right.

STATEMENT OF HARVEY ALTMAN, DEPARTMENT OF PSYCHIATRY, WAYNE STATE SCHOOL OF MEDICINE

Mr. ALTMAN. Good afternoon. My name Harvey Altman and I'm here as an official spokesman for the department of psychiatry in Wayne State University School of Medicine. My testimony before the committee today focuses on the need for increased State and Federal funding for research and education.

Even though Alzheimer's disease has begun to receive a considerable amount of attention in recent years, there is still a regrettable

lack of hard knowledge concerning this disease, or how it should be dealt with. This lack of information can be seen at all levels as primarily the result of a lack of sufficient training or exposure to the problems encountered in dealing with a particular population of people.

The following recommendations are therefore proposed:

That we develop an educational program specifically designed to address the problems of the aged and/or dementia. Currently very little training from either a research or a clinical perspective focuses exclusively on Alzheimer's disease.

Despite increased awareness of dementia in the elderly and despite very promising research in recent years, considerable growth is needed in programs designed to train investigators and academic leaders in this field.

There is presently a serious shortage of persons adequately trained and committed to research and teaching in dementia. In addition, there are too few settings with sufficiently qualified faculty and professional staff to train the needed professionals, even though it is only through greater awareness of the disease and its impact on man's society that we can help change public attitudes toward Alzheimer's disease.

The specific recommendations include, one, a concerted effort to include material on dementia in the curricula and examinations of all professional schools and training programs, such as medicine, nursing, pharmacy, associate health care disciplines, social work and law, at the undergraduate, graduate and postgraduate levels.

Two, additional funding to increase the number of career development awards for faculty and investigators capable of perceiving more independent education and research relevant to Alzheimer's disease.

Three, increased funding for the development of training programs specifically designed for the treatment of Alzheimer's disease, as well as to provide consultation to other services that are working in Alzheimer's disease.

Four, the amount and content of continuing medical education programs for those clinicians already in the field should be increased to include more materials specifically designed for problems associated with the aged and/or dementia. Information on dementia should be added to the State curricula for training of geriatric aides. In the State level, for example, the department of health should add an instructional unit on dementia to its curriculum for training geriatric aides.

An advisory committee with representation of pertinent knowledge and skills should participate in the development of the relevant material. Instruction on the impact of dementia should be included in State mandated inservice education programs of long-term care facilities. Specifications should be made within licensure and certification regulations that all long-term care facilities and programs include instruction on dementia and the techniques of management of demented patients with regard to their physical, intellectual and medical needs.

Dementia training centers should be developed. For example specialized programs need to be developed which would train family caregivers as well as the full range to professional providers in the

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management of the demented patient. Such a potential already exists through our major facilities of higher education as well as through the efforts of the Alzheimer's Disease & Related Disorders Association.

With respect to funding for research: Increase allocations for medical research so that a greater number of research projects—both RO-1 and PO-1—can be funded during a given period. At present too little money is available to fund research in this area. Significant advances and insights are constantly being made. However, a greater input needs to be made. One way to increase productivity would be by increasing the number of projects presently being funded by the various funding agencies. In addition, State and local agencies should be encouraged to support the research effort. At present, very little of the monetary support is derived from State and local sources. The Federal Government should also consider increasing financial support to smaller universities who wish to begin developing programs which would eventually make them eligible for funding under the National Institute on Aging Center Grant Program. At present such funding is selectively awarded to the larger, more internationally known institutions. There are areas of the United States which are not close to these centers, thus limiting access to a significant amount of the population.

Mr. CROCKETT. Now, doctor, I'm going to have to interrupt you because you can see how many others we want to hear from. It would be helpful if you could summarize your written presentations. Each of you who have written presentations, leave copies. They will be included in the official record of the proceeding, and you can then just summarize it in the 1 or 2 minutes, as I indicated at the outset, that we can make available to you.

Mr. ALTMAN. Sure.

Mr. CROCKETT. Thank you.

STATEMENT OF THELMA MEDREA, MOUNT CLEMENS, MI

Ms. MEDREA. Good morning. My name is Thelma Medrea, and I live at 4400 Calview Boulevard, Mount Clemens, MI. I am a member of the ADRDA, Ann Arbor chapter, and an active member in the Lansing Alzheimer's support group. I'm a member of the advisory council for the Senior Daytime Center at St. Lawrence Hospital, and I'm an avid advocate for Alzheimer's day care in this community.

However, my comments are on behalf of myself as a caregiver. As personal as these remarks are, the needs are the same for all Alzheimer's victims. We moved to Michigan from Ohio in August 1973, and since 1974, I have been a primary caregiver for my mother who came to live with us from Canada due to her inability to continue independent living. She'd been a capable person, and a former nurse, and community affairs, and respected church leader.

In 1976, we were involved in the sale of her home. I'm going to skip some of this and come down to some of the more pertinent things for here.

During 1983, we were faced with immigration and naturalization tasks of mother's permanent alien resident status and the many

documents needed to accomplish this. The following month she was hospitalized for 2 or 3 weeks, with a mastectomy and then rehabilitation with exercises was carried on by my daughter.

I've successfully worked through the initial fear, sorrow, and stress of the circumstances in our lives, but only because of a strong family network. My sister and I share care on a 3-month rotational basis in Michigan and Indianapolis. The on-going adult day care is scheduled in both States, now, for at least 3 days per week, and again, I cannot stress enough the importance of this community resource for respite care to the caregiver.

The costs are varied and I have a list of those costs, if they are requested. I reemphasize the need for education to family physicians and general public awareness so that if necessary, the choice of home care, with adequate preparedness and family assistance, would not make the task as burdensome.

Before ending this testimony, I must state that during the history of parenting and being a responsible citizen, I have not been an advocate of the Government interfering in the affairs of family life. I welcome the awesome privilege of responsibility of parenthood and assume whatever that territory offered.

However, the role is reversed, becoming a caregiver to a parent these past 12 years, and my concerns for the many others who might be in similar circumstances, the baby-boomer generation in particular, forces me to change a very stubborn opinion.

Thank you very much.

Mr. CROCKETT. Next?

STATEMENT OF JOSEPH HESS, CHAIRMAN, DEPARTMENT OF FAMILY MEDICINE, WAYNE STATE UNIVERSITY OF MEDICINE

Mr. HESS. I am Joseph Hess, the chairman of department of family medicine, Wayne State University School of Medicine. I would just emphasize three points very briefly, and I will file this statement.

The first is that we need additional resources to build into the medical school curriculum special preparation and training for aging. Other witnesses have emphasized this point. I would just cite as examples, special funding that's enabled us to get in programs on drug abuse and on health promotion in other areas. Extra resources are often needed to move the inertia of the very rigid and demanding medical school curriculum.

Federal funding can play a key role in making these changes. The changes not only need to occur at the undergraduate and medical student level, but also at the post-graduate level. My perspective is focused on primary-care physicians, the family physicians, the general interns who take care of the vast majority of elderly in this country.

Earlier witnesses have emphasized how rapidly the elderly population is growing, and as Representative Hollister stated, that's our major health problem facing this country today.

Second, is the need for similar assistance and incentives in the area of other health professions who are intimately concerned with the care of the elderly. This includes nursing, social work, pharmacy, and the allied health professions. One of the suggestions I am

making is that there be consideration given to career teaching awards in geriatrics and gerontology that would help to stimulate additional academic activity in the medical schools and universities in this country.

Third, and perhaps most importantly, is the need for new programs and demonstration projects to help us develop more cost effective ways of delivering humane and coordinated care to our older citizens. The fee for service system tends to be more fragmented and tends not to have the cost containment incentives built in that should be there.

I think we need to take a hard look, as a matter of national policy, into different systems of management, giving more flexibility and providing a mechanism within a managed care system for the differing levels of care that other witnesses have alluded to today.

Thank you very much.

[The prepared statement of Dr. Hess follows:]

HEARING STATEMENT FOR THE SELECT COMMITTEE ON AGING U.S. HOUSE OF REPRESENTATIVES

Mr. Chairman and Members of the Committee: I am Joseph W. Hess, Chairman, Department of Family Medicine, Wayne State University School of Medicine. Chief of Service at two Detroit Medical Center Hospitals and Director of the Geriatric Research and Education Program of the Department of Family Medicine.

I am pleased to appear before you today to identify some areas of concern for the present and future health care of the elderly citizens of our nation. My perspective in viewing our local and national health care needs for the elderly is that of an academic primary care physician with concern for the health professions educational and research responsibilities of the medical schools and universities. My perspective on Alzheimer's disease is within the broad context of the health care of the elderly.

It should be clear from previous testimony and information provided to this committee that the elderly are the most rapidly increasing segment of the population. For example a recent analysis of statistics for the state of Michigan showed that from 1970 to 1980 the population over sixty increased at a rate 5 times greater than the total population. For those 85 and older the growth rate was twice that of the population over age 60 or 10 times that of the population as a whole.

It is well known that the elderly, for reasons familiar to all of us, utilize more health services per capita and thus consume more health care dollars per capita than younger segments of the population. This fact, combined with the dramatically increasing number of older people, is a significant factor in the disproportionate growth in health expenditure compared to personal income (see attached figure). Thus, from a cost-containment standpoint as well as for humane and social policy reasons, federal, state and local governments and the private sector must work together to formulate more coherent, humane and cost-effective systems and mechanisms for addressing the medical, social and economic needs of our older citizens. I will make some concrete suggestions concerning areas where I believe the federal government can stimulate the development of systems and mechanisms which will more adequately address the complex array of problems we face now and in the decades ahead.

1. Incentive funding for better educaional preparation of primary care physicians (family practitioners and general internists) in both the biomedical and patient family management aspects of health care for the elderly including Alzheimer's disease.

The elderly are the most diverse, complex segment of our population physiologically, emotionally, economically and socially. Concepts and principles of medical care which hold true for younger people have to be modified and adapted to the individual circumstances and needs of the elderly. The differences pertaining to the elderly range all the way from the amount and types of diagnostic and therapeutic procedures that are appropriate to issues of home care, family involvement, community resources and support systems.

Primary care physicians deliver the vast majority of medical care to the elderly and should continue to do so in the future. However the current generation of physi-

cians in practice have had no special basic educational preparation for this very complex task. Continuing medical education programs are beginning to fill the void for phusicians already in practice but for many it will be too litle and too late. To do an adequate job the biomedical and attitudinal education preparation should begin in medical school and continue on with increasingly sophisticated learning experiences throughout the postgraduate and practice phase of most physicians, particularly those in the primary care fields of family practice and internal medicine.

The majority of expenses for medical education are paid from state, private and tuition sources. However it has been repeatedly demonstrated that relatively small federal incentive grants in the range of $100,000 to $200,000 per year per medical school over a 3-4 year period can have a substantial impact on the introduction of new curricular offerings and learning experiences of medical students. In our own medical school. We have seen new subject matter introduced into the curriculum in the areas of health promotion/disease prevention, alcohol and substance abuse, occupational medicine and many others. A similar program funded through The Bureau of Health Manpower could have a substantial longterm effect in the area of geriatric medicine. These funding incentives should include the requirement that appropriate new learning activities be developed at both the medical student and residency levels. Career clinical teacher awards in geriatric medicine could help solidify and maintain the innovations introduced into curricula.

2. Incentive funding for better preparation of personnel in other health profession disciplines intimately concerned with the delivery of health services to the elderly, this includes nursing, social work, pharmacy, physical and occupational therapy.

Cost effective comprehensive care of the elderly requires close cooperation and teamwork between the patient, the patient's family and support system and the health professionals noted above. Thus each of the disciplines can be stimulated to move ahead more rapidly to prepare graduates for the enormous task ahead of us. The training institutions need the additional resources necessary to revise curricula, train or acquire new faculty with expertise in geriatric care and to develop new affiliations and arrangements for hands on clinical experience in caring for both institutionalized and non institutionalized elderly. The concept of Career Teacher Awards in gerontology in these disciplines is also worthy of consideration.

3. Funding of Research and Demonstration projects to develop and evaluate new organizational and management models for maintaining health and social supports for the elderly at the lowest possible cost consistent with humane care.

The example of Alzheimer's Disease and related disorders, which is the main subject of this hearing, can be used as an example of the comprehensive type of assessment and care that is required for many health conditions which afflict the elderly. When family and/or friends first begin to note changes in behavior and mental function it is important that they have access to a concerned, competent physician to perform the diagnostic assessment that is necessary to determine whether the cause of the problem is treatable and reversible before more serious damage occurs. Typically this can be done on an outpatient basis providing there is insurance coverage to do it this way. However in a few selected complex diagnostic and/or social situations, all of the necessary work cannot be accomplished outside of the hospital and short hospital stays may be required. Currently there are barriers to doing this under medicare in that hospital admission for suspected Alzheimer's Disease alone is not reimbursable.

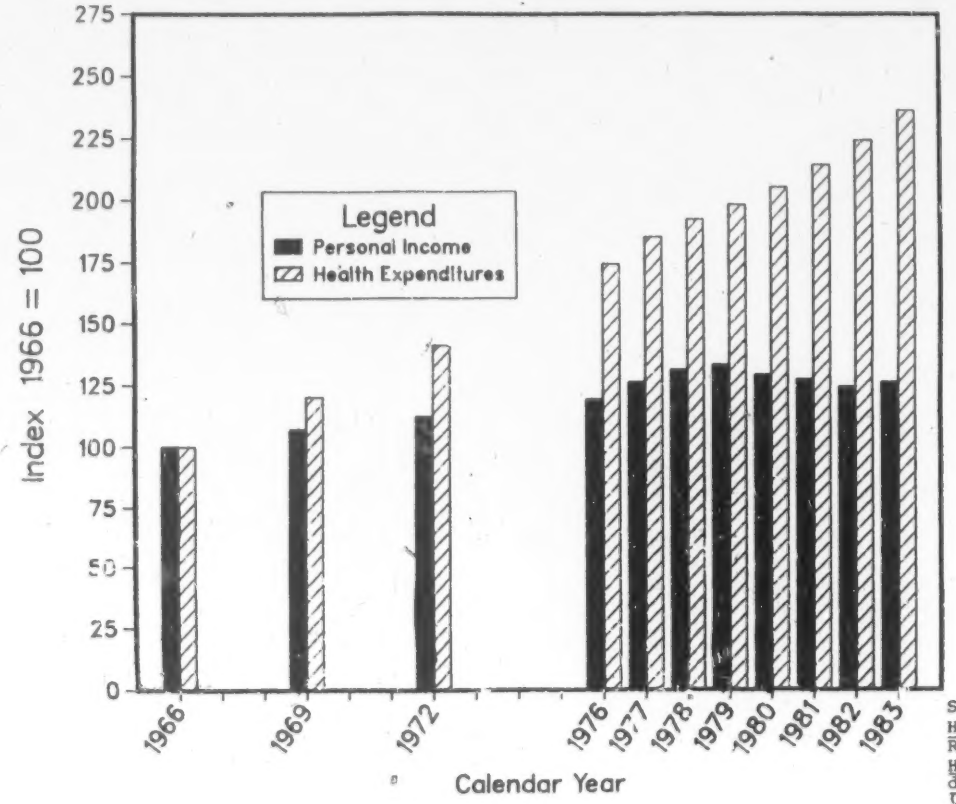
In later stages of Alzheimer's Disease, many victims are no longer capable of self care and require more assistance than family and other supports can provide in the home. When this stage is reached there needs to be efficient mechanisms for evaluating the specific medical, nursing and functional support needs of the individual and then a well researched decision made as to the location, type and intensity of care required. Multiple intensity levels should be available starting with supports provided in the home and including respite centers, day care centers, night care centers, residential nursing centers, and nursing homes with appropriately trained staff and support services of varying intensity and cost. The guiding management principle should be to care for the patient as close to home and involving family and other supports as much as possible coupled with the capability to move patients up the cost and intensity ladder as determined by the need for care.

What I am trying to describe very briefly is an efficient, coordinated care model which has flexibility and fiscal Accountability in the use of an appropriate range of resources for a defined population of older people. The Social HMO is one such concept which should be developed and tested but other models should also be considered. The demonstration models I am suggesting could provide excellent educational environments for training and stimulating the intellectual and emotional involve-

ment of future generations of health professionals in exploring new and better ways to care for the elderly.

The three proposals I have made are not new or original. I am merely adding my voice to that of many others who are thinking about and planning for the years ahead in the health care field. If we do not bring thoughtful planning for educational and health care delivery for the elderly into national and local policy now, we will pay a very high price in the future for failure. The price will be paid both in terms of escalated demands for health care spending and in human stress, suffering and loss of dignity for the elderly in our society.

INDEX OF PER-CAPITA INCOME AND HEALTH EXPENDITURES, ADJUSTED FOR INFLATION, 1966 – 1983



Source: Michigan Health Care Costs Review: Personal Health Care Expenditures, 1966-1983 OHMA, DMB, 1985

Mr. CROCKETT. Thank you, Doctor Hess.

STATEMENT OF ELMER BENSON, DETROIT, MI

Mr. BENSON. I'm Elmer Benson. I'm the chief executive officer of two United Methodist Retirement Homes, one here in Detroit and one in Chelsea. At the Chelsea facility, working with the Institute of Gerontology of the University of Michigan and with the encouragement and support of the Michigan Department of Public Health, we have developed an extremely successful care unit for persons suffering from Alzheimer's and related dementias.

I might tell you that it is going to be on public television soon, a 27-minute documentary on it, and I encourage you to look for it. I had a lot of words to say, Representative Crockett, but following your direction, I'm going to have it entered into the record. I'm only going to say that, in this special-care unit, we have been able to see a dramatic improvement in the quality of life of the people who are in the home; we have seen, with our special programs and a supportive environment, a marvelous impact on patients and families.

We've seen rejection, despair, and hopelessness replaced by excitement, joy, fulfillment, and peace. We've been able to do it on limited resources at a figure of about $15 a day less than private pay nursing home rates. And we would encourage the Congress to support research but also urge you to consider financial support of victims and families.

And thank you.

[The prepared statement of Mr. Benson follows:]

PREPARED STATEMENT OF ELMER BENSON

I am Elmer Benson from Ann Arbor, Michigan. I am employed as the Executive Director (C.E.O.) of the United Methodist Retirement Homes, which owns and operates two continuum of care facilities in Southeast Michigan: The Boulevard Temple United Methodist Home in Detroit, and the Chelsea United Methodist Home in Western Washtenaw County. I also serve as the President of the Michigan Non-Profit Homes Association, the Michigan affiliate of the American Association of Homes for the Aging.

At the Chelsea United Methodist Home we are operating a sucessful and acclaimed residential care unit for elderly persons suffering from Alzheimer's or related dementias. Developed over a period of several years of joint efforts with a research team from The University of Michigan Institute of Gerontology (led by Professor Dorothy Coons) and Chelsea Administrator Catherine Durkin, this program and facility has dramatically increased the quality of life of its residents.

We have created in our "Wesley Hall" a living environment designed for older people with mental impairment. The area is designed consistent with therapeutic milieu principles and with emphasis on spatial adaptation, cueing and aging. A sense of intimacy exists in this home like setting. General use areas, i.e., living room, dining room, den and kitchen are easily accessable. Single resident rooms are individualized with personal possessions. Color coding, large print signs and other orientation features enable residents to function at their maximum level.

Activities with clear and meaningful expectations are geared to individual capabilities. Staff is specially trained to work with residents on self-care. Families and children are incorporated into programming. This climate has become one of relaxed camaraderie with much sharing and mutual support.

We plan to expand our special care unit capacity both at Chelsea and at Boulevard Temple to meet a very large community need for sensitive, effective care of those afflicted with Alzheimer's or related dementias. We have seen through our special program and supportive environment a marvelous impact on both patients and families: Rejection, despair, and hopelessness replaced by excitement, joy, fulfillment, and a sense of peace. We have been able to deliver this care at rates of $15.00 to $20.00 less per day than private room nursing home charges.

We urge this distinguished committee to recognize in what we have been able to achieve on a small scale and limited budget, what dramatic results could be achieved nationally with federal funding of research, staff development, and consulting services, AND FINANCIAL SUPPORT FOR VICTIMS & FAMILIES

We understand that Public Television viewing of a 27 minute documentary on our Wesley Hall is scheduled within several months. We urge you personally to see for yourselves the potentials that can be achieved and expanded with your support.

Respectfully submitted,

Elmer J. Benson

Elmer J. Benson
Executive Director

Mr. CROCKETT. Thank you, Mr. Benson.

STATEMENT OF SID GILMAN, M.D., ANN ARBOR, MI

Dr. GILMAN. Mr. Crockett, Mr. Conyers, my name is Sid Gilman. I'm chairman of the department of neurology at the University of Michigan in Ann Arbor.

I have a statement that I will leave into the record, but I'd just like to summarize it briefly for you.

Mr. CROCKETT. Very well.

Dr. GILMAN. We have active research in both the basic and the clinical areas concerned with Alzheimer's disease at the University of Michigan. We also have a cognitive disorders clinic where we see people with memory problems. It's operated by Dr. Norman Foster. Last year we saw 300 patients. This year we are going to see many more.

Over 60 percent of these people have Alzheimer's disease. We've been struck at the number of people who are referred to us from other physicians with an incorrect diagnosis. We need a good deal of education, both in the public sector and among physicians in the State of Michigan.

In addition, we have some basic research that is coming up with exciting new findings. We have discovered a basic biochemical defect in the brains of patients with Alzheimer's disease, and we have studies that demonstrate with particular kinds of energy, called positron emission tomography, or PET scanning, that there's a distinctive pattern of glucose utilization in people with Alzheimer's disease.

Constantly, we need funds to support this kind of research and also to support some of our clinical and research activities. We are concerned about the cutbacks in Federal funding for such endeavors. We've been very successful ourselves in bringing in grant support, but we constantly try to encourage our trainees themselves to become medical investigators as we are.

We are very hopeful that the bill that's being discussed at these meetings will be successfully passed. We see a substantial need for additional funding in these areas.

Thank you.

[The prepared statement of Dr. Gilman follows:]

PREPARED STATEMENT OF SID GILMAN, M.D.

My name is Sid Gilman. I am Chairman of the Department of Neurology at the University of Michigan and am actively pursuing research in degenerative neurological diseases, including Alzheimer's disease. Several other faculty members in my department are also actively pursuing basic and clinical research in Alzheimer's Disease. Our Cognitive Disorders Clinic, which cares for people with memory loss, evaluated over 300 people last year, over 60% of whom had a diagnosis of Alzheimer's disease. This year the number of patients we are seeing with Alzheimer's disease is even greater.

The number of patients seen in our clinic reflects only a small percentage of those afflicted with Alzheimer's disease in the state of Michigan and many others are still receiving inadequate evaluation and care. We continue to see both patients who have reversible causes of memory loss who have been misdiagnosed as having Alzheimer's disease and others in whom memory loss and intellectual deterioration were regarded as simply due to aging. From my perspective, improved public education and physician training are clearly needed.

Furthermore, I am struck by the progress which is being made in Alzheimer's disease research and the excitement which this has stimulated among my collegues. For example, in the last year, our laboratories have demonstrated a specific biochemical defect in the brains of patients suffering from Alzheimer's disease and we have shown that PET scanning can distinguish between Alzheimer's disease and other kinds of memory loss. While there are limits to what medical research can do and the speed at which it can advance, we must not stifle enthusiasm and inhibit research at the very time we are making the greatest strides. Recent cuts in federal support of medical research are already having that effect. Further cuts in funding of medical research will particularly impair progress in understanding Alzheimer's disease. For many years, this disease was thought to be hopeless and was not of major research interest. However in the past few years, significant advances in our understanding of this disease, some made in our own laboratories at the University of Michigan, have completely changed this perspective. We must encourage young medical scientists to enter this field of research and build upon what already has been gained. We cannot permit lack of research funds to prevent recent advances from being applied to patient care and the development of new treatment strategies.

I am particularly able to speak to the importance of several provisions of House Bill 2280 which apply to this situation. I strongly support the plan to extend the current Alzheimer's Disease Research Centers Program by funding twenty such centers throughout the United States. These centers should continue to be awarded on a competitive basis though the normal NIH peer review system. These centers provide focuses of expertise in both clinical care and basic research. The increase in research funds that these centers represent will substantially increase the enthusiasm of neurologists in training and junior investigators who are considering applying their talents to the field of Alzheimer's disease. There is a tremendous need to provide training funds at a time when changes in health care financing and increasing costs of medical education are forcing many of the brightest young minds to leave medical research. It would be a disaster to abandon the next generation of medical scientists who are just now considering the possibility of entering medical research.

Last Wednesday evening, April 9, medical scientists from throughout the state of Michigan who study Alzheimer's disease met to discuss their work and what could be done to improve their productivity. Although I am not a spokesman for this group, several specific needs were outlined. They unanimously supported House Bill 2280 and felt that this bill's research provisions and that of Senate Bill 1835 would substantially improve research efforts in Michigan. Second, they agreed that training funds are needed to improve the quality of care and diagnosis of Alzheimer's disease. Third, it was clear that a registry of patients with Alzheimer's disease is needed to determine the incidence of this disease in Michigan and factors that may contribute to its prevalence. Finally, these scientists felt that funds must be provided to assist families in obtaining post-mortem examinations of their relatives who had died of Alzheimer's disease. Post-mortem brain examinations remain the only way to confirm the clinical diagnosis of Alzheimer's disease and are necessary to permit the refinement of our abilities to diagnosis this disease before death. Such examinations will also permit expanded studies in the basic structure and biochemistry of the brain in this illness.

Passage of legislation such as House Bill 2280 is needed to encourage continued progress in medical research. Such progress can not be taken for granted. Alzheimer's disease is a major national health problem. Its solution will require all the energy and innovation that modern medical research can provide.

Thank you.

Mr. CROCKETT. Thank you, very much. Next witness.

STATEMENT OF DR. ROGER MORRELL, ALLEN PARK, MI

Dr. MORRELL. Good morning, Mr. Crockett, Mr. Conyers. I'm Dr. Roger Morrell. I'm chief of neurology at the VA Medical Center, Allen Park. I'm not speaking as a VA official. I'm speaking personally and as a professional.

My opinions represent 11 years of experience as the chief of two VA neurology services, as a professor of neurology at Wayne State University, as past chair of the medical advisory board, Detroit ADRDA, and as past organizer of the Kellogg Foundation-VA sponsored international work group evaluating patterns of care and research in the dementias.

My father, a retired Air Force colonel and a chemical engineer awarded the primary patents in high-octane gasoline and synthetic rubber, died of Alzheimer's disease in the U.S. Naval Medical Center at age 92 last March. The VA now has a growing population of veterans over age 65 at risk for Alzheimer's. These numbers will increase by the year 2000 to 10 percent to 30 percent of all veterans.

The VA has responsibility for the management and treatment of these individuals, as well as the care of their families. As one of the world's largest health systems, it has an opportunity to make significant contributions but at this time does not meet minimal needs of patients or their families in connection with veteran care.

First there is no uniform protocol for diagnosis of dementia throughout the VA. Those of us who met in Washington as a member of the national ad hoc committee to provide field guidance, we are told that our product, after months of work, was not able to be funded for distribution.

That product would have included a computer program for the development of a data base which is necessary for a national level identification of veterans with dementias according to ICD9 dementia codes. Second, VA facilities are generally inadequate to care for dementia patients. Third, eligibility and utilization criteria for dementias, including DRG ratings, are inadequate and varied regionally or by facility. Some families have to resume responsibility for a demented veteran after 6 months of care in a VA facility. Fourth, the VA has virtually no day care or respite facilities.

Solutions to the most serious deficiencies have been devised or suggested in parts of the VA or the private sector, but what is now required is to establish national level criteria and specifications in the critical areas, and to allocate resources sufficient not only to implement, but to sustain the VA mission in behalf of veterans and ultimately to the public.

Thank you.

Mr. CROCKETT. One question, doctor. Is your critique addressed to the VA nationally or are you talking about the local situation?

Dr. MORRELL. Both, both, yes.

Mr. CROCKETT. I see.

Dr. MORRELL. Each reflects the other.

Mr. CROCKETT. Thank you.

Dr. MORRELL. Yes, sir.

STATEMENT OF GREG LUNDSTED

Mr. LUNDSTED. My name is Greg Lundsted. I have my masters degree in social work. However, I am speaking as a professional and not representing the Department, and the views I'll be talking about are my experiences with people who I have worked with in foster care in adult foster care homes who have Alzheimer's or other types of dementias.

I have found that foster care for a number of people who are forgetful or who have been diagnosed as Alzheimer's has been a very rewarding experience, not only for the individual but for the person's family. There has been a cost saving to both the family, the individual, and to the State and Federal Governments, because we have been able to keep this person out of a nursing facility, where they then would have been eligible for Medicaid.

They had sufficient income that they could live in foster care, using their own funds. We were fortunate in that we were able to find foster-care-home providers who were tuned into the needs of the elderly person. These people would do such things as visit with the demented individual, and would encourage them to do what they wanted to help around the foster care facility, as long as they were not doing anything that would create a danger for themselves or others. There was an encouragement for group activities in which the person would be included, and there seemed to be a general protection by other members of the foster care facilities for the demented person.

In doing research on my master's, I found that there are about 25 percent of the people in nursing homes today who could be placed in less restrictive settings. However, I found that both the State and Federal regulations regarding Medicaid encourage the placement of people in foster care. The Federal regulations regarding SSI, nonexempt property limitations for homes that encourage the person. This is based on the fact that people who qualify for Medicaid in SSI will not qualify—excuse me, they can qualify for Medicaid but not SSI, and be placed in a nursing home.

However, they cannot qualify for the SSI and be placed in a foster care home because of the home setting. We have other individuals who, because of high medical expenses and high income from Social Security and possible retirement, which would just put them over the SSI income level—and we're talking a $2 level, if they're over, they're drawing $2 less than what the SSI payment level would be—are not eligible to use the Medicaid. To be eligible for Medicaid, they would have to incur a spend out.

This can force people into nursing homes, rather than allowing them to be placed in a foster care home. I would propose that No. 1, that the SSI nonexempt property limitation for home setting be reevaluated to exempting it for people who go into foster care because of health problems.

I would also suggest that another level be set up for the projected income level for Medicaid that would be based on the living arrangement of the individual. Presently you have two: long term care, which is basically nursing care, and all others, which comes down to independent living.

And I would suggest you look at possibly two or more levels that would correspond to the SSI payment to adult foster care in homes for the aged.

Thank you.

Mr. CROCKETT. Thank you, very much.

STATEMENT OF HENRY WISNIEWSKI

Mr. WISNIEWSKI. My name is Henry Wisniewski, and I'm a guest here. I'm director of a research institute in New York. I spent 20 years of my life studying the basic phenomenon of Alzheimer's disease. Mr. Chairman, I want you to know that we are very close to finding the answer to what is the basic cause in this disease. As you know, Dr. Zaven Khachaturian of the Aging Institute asked for 20 research centers. They hardly got money for 10. We are not supported and we will be not able to come up with the basic answers if you are not supporting us.

I think that basic research right now is cut much harder than any other part of Federal funds. We already have been cut 5 percent. We are being said to be cut another 7 percent. We cannot bring the day where so very few can make such a difference to so many of you.

So, I ask you to support the basic research and not so many of these things.

Mr. CROCKETT. Thank you.

STATEMENT OF DIANE WILKINS, DETROIT, MI

Ms. WILKINS. My name is Diane Wilkins, and I'm executive director of the Alzheimer's Disease Related Disorders Association for the Detroit area chapter. I wanted to say first, I think we are all honored here today to be able to make remarks to three of the most eloquent and staunchest supports of human services and human rights in the U.S. Congress. And I'm very pleased to do that.

We at the Detroit area chapter of the Alzheimer's Association are a nonprofit voluntary health organization. As you know, we provide a variety of services to patients and their families, such as counseling, family support groups, and a brand new respite program. Through the leadership and support of the Michigan department of mental health, we are providing a pilot project respite program for families in our area, and we are very excited about that.

We provide education to the public; we promote research in the area, among a variety of other services. The Alzheimer's Disease Related Disorders Association in the Detroit area receives approximately 500 calls each month, 500 to 600 calls each month reflecting a lot of the concerns that were talked about today.

I want to just touch briefly on three of them: The first is the problem of financing long term care. It's been very eloquently discussed here today. I just want to mention that we see that in the flesh daily, continually, hundreds of times each week. The typical scenario is a couple perhaps in their seventies, even eighties, that have saved, have worked, perhaps are living on a very modest retirement income, as Carol Jones had talked about earlier.

Suddenly Alzheimer's hits, and that family is not eligible for Medicare because Medicare will not cover the nursing home; they are not eligible for Medicaid because they are perhaps earning a modest income of $10,000 to $12,000, $11,000 retirement, or perhaps they have small savings that they've saved over the last 50 years.

They are ineligible, and that hits very very hard. And I just want to emphasize that all of those stories that people told today we see every single day, and those people are caught in a catch-22 for which there is no relief. There is no opening. There is no safety net. And our hands are tied as to how to help those people and how to move them through.

Another area I want to mention is the area of family support: the geometrically increasing need for family support groups. We operate family support groups in this area. It's free of charge. We cannot really keep up with the need, because as our population ages, as you know, that need is geometrically increasing. We get calls that we cannot even handle. So we would like to support Federal initiatives for support of family support groups where families can come and get help, get support and encourage one another.

Third area is respite care, as I touched on briefly. We have a pilot project through the department of mental health, and we would encourage increased efforts at the Federal, State, local, private sector levels for respite care. It's a very immediate and urgent need.

I want to thank everyone and thank the Congressmen.

Thank you very much.

Mr. CROCKETT. Thank you very much.

STATEMENT OF JIM ERICKSON

Mr. ERICKSON. Very briefly, thank you. My name is Jim Erickson. I'm with the mid-Michigan chapter of ADRDA and I'm the treasurer for our chapter. We serve about 12 counties. In the last 7 years, we've given moral and emotional assistance to over 600 to 700 families in a relatively sparsely populated area.

I just wanted to share with you some of the things, three things that every family caregiver faces and the emotional trauma—and hopefully, this wasn't particularly highlighted earlier today.

But there has been that journey and that real challenge of identifying what is the problem with my loved one, what is the situation, and that's been very very difficult because some of the responses and answers have not been very clear.

And within that first concept is the question of acceptance. We accept things at varying degrees but you must accept the reality of this before you can move and really begin to move and serve the patient. And you have to often cope, and this is family situations, and again the traum of this illness is such that you have adult children who don't believe that that's happening to their parent; brothers and sisters of the patient and a caregiver is often in the middle of a very difficult situation.

I believe personally that that's step No. 1. The second step is the biggest step in this three-step process, and that in my judgment, is recognition. I hope this isn't too much at odds with some of the points that have been made—recognition that the care will ulti-

mately be beyond the ability of the home caregiver, and for many many people this institutionalization is the biggest step they will face in the whole process.

Whether it is for adult foster care or a nursing home, that is the most traumatic step of all. And if you do have the fortune of going to adult foster care because the patient isn't so completely disabled, when you have to take that next step, it's not quite as difficult because you've taken the big emotional step.

And finally, the end, and that often is a blessing because if you've mastered one and two, the end comes as a friend. So I just wanted to touch on this trauma and this challenge that the caregiver and the family faces, and it often is very very helpful if there can be somebody in every family who can play the role of the heavy and have the guts to make the big decisions, because you do face big decisions.

And the longer that they are postponed, the bigger they become.

Thank you, Mr. Chairman.

Mr. CROCKETT. Thank you very much.

STATEMENT OF SHARON BALASCO, FLINT, MI

Ms. BALASCO. My name is Sharon Balasco, and I'm a member of ADRDA from Flint, MI. My father has had long term Parkinson's disease. About 5 years ago, he became a vegetable. He could not touch his nose, he can't move his bowels. He could do nothing but yet he is considered a basic care patient so my mother received no help. My mother will probably die before my dad because of the financial and emotional strain of this illness.

Thank you.

Mr. CROCKETT. Thank you.

Congressman Conyers, have you any comments you would like to make in closing?

Mr. CONYERS. No, Mr. Chairman, but to congratulate you for bringing these hearings to our city.

Mr. CROCKETT. Well, I think the congratulations really should be extended to Wayne University and to the Medical School here. The hearing was intended to complement the conference, the 3-day conference that is going on.

I hope that those of you who are registered participants in the conference have benefitted from this hearing as much as I have and as much as I'm sure Congressman Hertel and Congressman Conyers have. I will say that, for the benefit of those whose statements we took last, don't feel that merely because you were not seated here testifying, that your comments will not be noted.

They will all be included in the record. While I cannot guarantee you that the members of the committee themselves will read the entire record, on the contrary, I can assure you they will not, we do have a very competent staff and it is the function of that staff to read all of these statements and to analyze and summarize them, and then present the essence of the report to the members of the committee.

That report will guide us in devising answers, we hope, to some of the problems that you have raised, and recommendations that we will make to the legislating committees. So you have been ex-

tremely helpful and I'm extremely grateful that we were able to come to my district, the 13th Congressional District, to have this kind of hearing.

I would like to turn the meeting back to the Wayne University officials for any comments they might have.

Mr. DOUGLASS. I just have a heartfelt word of gratitude for all of you. On behalf of myself, Richard Douglass, and the department of family medicine, department of community medicine, and the rest of the departments, ADRDA, the Levine Institute, if you haven't registered for the conference, please do.

There's a lot of action this afternoon. There are facts and issues being raised this afternoon on the black family on Alzheimer's that have never had a forum before in this State or anywhere else in the country in the context of Alzheimer's disease. Please attend.

Tomorrow we have a program for primary care medicine. We have another family program tomorrow afternoon. There are biomedical programs each day. All of this is for you. We set the rate at $100 for 3 days to accommodate home health aides and psychiatrists and everything inbetween.

Everyone should be able to afford this. That's the intent. Please stay, please learn, please share with us, write with us, correspond on an ongoing basis with the people at the conference, network with each other, and help us to solve the problem.

Thank you.

[Whereupon, at 11:57 a.m., the hearing was adjourned.]

APPENDIX

PUBLIC POLICY RECOMMENDATIONS

Five Alzheimer's Disease and Related Disorders Task Force Reports

Jim Strong

February 10, 1986

--distributed by --

East Bay Chapter

Alzheimer's Disease and Related Disorders Association

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BACKGROUND

This paper was originally prepared in November, 1985 to satisfy the requirements of a U.C. Berkeley inter-departmental studies course, "Alzheimer's Disease: Biological and Social Dimensions", (professors Meridth Minkler and Paola Timiras). It has been updated and re-issued to serve as an aid to fellow Alzheimer's activists, legislators and future task forces and commissions.

Alzheimer's Disease has burst upon the public policy scene, beginning with the founding of the Alzheimer's Disease and Related Disorders Association in 1979. In the last two years, five task forces and commissions have completed reports. The work of these groups are a particularly useful resource since their diverse memberships have found compromises between disparate views and tempered compassion for the victims of Alzheimer's Disease and related disorders (ADRD) with political reality.

The Rhode Island Legislative Commission issued its report in May, 1984. This was followed in September by the report of the U.S. Dept. of Health and Human Services Secretary's Task Force on Alzheimer's Disease. In May of 1985, The Massachusetts Governor's Committee on Alzheimer's Disease issued its report. Maryland Governor's Task Force on Alzheimer's Disease and Related Disorders issued their report the following month. The recommendations of the Kansas Alzheimer's and Related Diseases Task Force are a preliminary version, reported in December, 1985.

METHOD

The 114 recommendations presented in the five reports have been grouped in five categories. The categories; Financing, Education, Care, and Research were based on a division of work of the current California Alzheimer's Disease Task Force. An additional category, Coordination, emerged after reviewing the reports' recommendations. Some recommendations made significant statements in more than one of the five areas. These appear, with relevant titles, in all relevant lists. All titles have been assigned by this author.

Recommendations have been edited to a similar style of presentation: [actor(s) -- is to (are to) -- action]. Some have been shortened to fit the limit of 500 characters imposed by the database management software. The abbreviation, ADRD, has only been used when the original text referred to Alzheimer's Disease and related disorders. Readers interested in original wording and more detail are urged to obtain the reports.

FINANCE RECOMMENDATIONS

ACUTE CARE - ADJUSTED REIMBURSEMENT

The State is to review and, if indicated, adjust its reimbursement policies for acute care so that account is taken of the additional costs required for the care of demented patients. [Maryland, p. A-2]

ELIGIBILITY FOR AID

Federal and State authorities are to ease eligibility and service restrictions so that dementia victims and their families are not impoverished before eligibility (for Federal and State aid) can be established; and so the needs of ADRD patients can be met in the least restrictive setting appropriate to their needs. [Maryland, p. IX-6]

FAMILIES LIABILITY TO PAY FOR STATE HEALTH CARE

The State is to review the formula for determining relatives' liability for paying for a patient's confinement to a State health care facility. [Maryland, p. A-4]

FAMILY FINANCING OF CARE - DIVISION OF ASSETS

A division of assets law is to be passed to prevent the abject poverty of the well spouse in his attempts to provide for the care of the ill spouse. [(Prelim.) Kansas, p. 1]

FAMILY FINANCING OF CARE - LEGAL ISSUES

The Governor is to appoint a commission or committee to deal with legal issues of great concern to patients with ADRD, including: distribution of property and burden of care, trusts, guardianships, conservatorships, durable powers of attorney, living wills, the patient as research subject, family participation in medical care and the administration of psychotropic medication and the jurisdiction of the courts. [Massachusetts, p. 12]

FINANCE RECOMMENDATIONS

FUNDING DEMONSTRATION PROJECTS

The Long Term Care Work Group is to develop and recommend funding for at least four demonstration projects. These are to take different approaches to providing a coordinated, systematic, and creative approach to serving the patients and families who suffer from ADRD. Funding is not to exceed $500,000/project. Either the Executive Office of Elder Affairs or of Human Services is to carry out actual program planning, funding and evaluation. [Massachusetts, p. 10]

GRANTS FOR TRAINING DEVELOPMENT AND SCHOLARSHIPS

The State is to provide grants to major educational institutions to develop training programs for the management of demented patients and to provide scholarships for trainees. Trainees would include family members and a full range of professional providers. [Maryland, p. IX-4]

HOME CARE - FINANCIAL INCENTIVES

The State is to furnish financial incentives to families averting institutionalization costly to the State. Incentives might include: financial assistance or tax relief; incentive grants to family caregivers; and allowing offsets, against a family's reimbursement obligations for State/County services, based on the families own services and expenses in maintaining a patient at home. [Maryland, p.IX-6]

HOME CARE AND DAY CARE - GRANTS

The State is to provide grants, awarded by local Geriatric Evaluation Service teams, to individuals for purchase of adult day care and home care. [Maryland, p. A-3]

INSURANCE - ELIMINATE PREJUDICE AGAINST ADRD

The Legislature is to direct the Insurance Commissioner to examine all medical disability insurance policies sold in Kansas to ensure that these policies are not prejudicial against victims of ADRD. [(Prelim.) Kansas, p. 3]

INSURANCE - EXTENDED CARE REIMBURSEMENT

The State is to modify the Rhode Island Catastrophic Health Insurance Plan (CHIP) to provide reimbursement for a determined fraction of the expenses of extended care, either incurred within the home or in licensed institutions. Funding for CHIP is also to be increased to fulfill this expanded commitment. [Rhode Island, p. 3]

FINANCE RECOMMENDATIONS

INSURANCE - LONG-TERM CARE

State insurance laws are to be amended to require that all health insurance policies include an option for coverage of long-term care. Coverage is to include care received at nursing homes, home health care, respite and custodial services and is to include coverage of both preexisting and current diagnosis of ADRD. [(Prelim.) Kansas, p. 1]

INSURANCE - LONG-TERM CARE

The State is to induce the insurance industry to offer actuarially supportable long-term care insurance coverage. Dementia victims are not to be categorically excluded. [Maryland, p. IX-6]

INSURANCE - LONG-TERM CARE

A State Commission is to be established to study the level of need for private long-term care insurance, barriers blocking the development of such insurance, and strategies to encourage the development of such insurance. [Massachusetts, p. 13]

INSURANCE - LONG-TERM CARE

The State is to encourage Blue Cross/Blue Shield of Rhode Island to provide actuarially sound coverage of chronic diseases, such as Alzheimer's Disease, which require extended nursing home care. [Rhode Island, p. 3]

INSURANCE - RETROACTIVE DETERMINATION OF DISABILITY

The Massachusetts Congressional delegation and the state agencies concerned are to try to influence the Social Security Administration to implement a longer period of retroactive determination of disability for Alzheimer's Disease. (This would enable an individual who lost a job due to the impact of the disease prior to diagnosis to collect disability payments if a diagnosis was made in a later stage of the illness.) [Massachusetts, p. 12]

INSURANCE - RETROACTIVE DETERMINATION OF DISABILITY

Private employers should permit a longer period of retroactive determination of disability for Alzheimer's Disease. [Massachusetts, p. 13]

FINANCE RECOMMENDATIONS

INSURANCE AVAILABILITY AND REIMBURSEMENT RATES

Medicaid, Medicare, Blue Cross/Blue Shield, and other insurers, as well as the Rate Setting Commission and the Department of Public Health are to work together: 1) to establish an appropriate policy with respect to hospitals, nursing homes, adult day-health programs and other providers, and 2) to adjust physicians' and other providers' reimbursement rates to establish appropriate compensation and avoid financial disincentives for provision of such services. [Massachusetts, p. 12]

INSURANCE FOR PATIENTS' LIABILITIES DURING RESPITE CARE

The State is to encourage insurance carriers to provide that insurance policies covering homeowner liability will extend to liabilities incurred by ADRD patients during day care and in-home and out-of-home respite care. [Maryland, p. A-4]

MEDICAID - LENGTH-OF-STAY FORMULA CHANGES

The State is to adjust Medicaid length-of-stay reimbursement formulas according to Diagnostic Related Groups in the case of hospital service to ADRD patients. [Maryland, p. A-2]

MEDICAID AND STATE HEALTH INSURANCE COVERAGE

Alzheimer's Disease deserves to be beneficiary of society's safety net for organic illnesses through mechanisms such as Medicaid and the Rhode Island Catastrophic Health Insurance Plan. [Rhode Island, p. 2]

MEDICAID DEMONSTRATION GRANTS FOR HOME AND DAY CARE

The State is to adopt a more energetic approach toward seeking Health Care Financing Administration waivers through Medicaid demonstration grants to enable provision of home care and day care under Medicaid. [Maryland, p. A-2]

MEDICAID FUNDING OF TRANSPORTATION TO MEDICAL CARE

The State Medicaid agency is to ensure the availability of transportation, under Federal law, to necessary medical care. [Maryland, p. A-4]

MEDICAID REIMBURSEMENT FOR PSYCHIATRIC TREATMENT

The State is to modify its Medicaid reimbursement policy to appropriately support psychiatric consultations for the treatment of behavioral disturbances secondary to dementia for Medicaid patients in nursing homes. [Maryland, p. A-2]

MEDICARE - LIMITS ON COVERAGE

In determining whether services for Alzheimer's patients are subject to the $250 limit placed on psychotherapy, the nature of the physician's service should be the deciding factor, not the diagnostic code. (Current Medicare statute limits medically appropriate physician services provided outside of the hospital setting for patients with Alzheimer's Disease when coded as a mental disorder.) [U.S. Dept. of H&HS, p. xv]

MEDICARE - LONG-TERM CARE

The Federal Government is to create a Medicare, Part C program to cover specified long-term care services, both institutional and non-institutional. As a first step toward that goal, the Massachusetts Congressional Delegation is to be asked to introduce legislation directing the Secretary of the Department of Health and Human Services to establish a Blue Ribbon Commission charged with developing a concrete Medicare reform plan. [Massachusetts, p. 13]

REGULATIONS - CLARIFICATION

The Medical Assistance Policy Administration is to prepare a comprehensive explanatory document, aimed at overcoming widespread information gaps and misinformation about the Maryland Medical Assistance program. [Maryland, p. A-4]

REGULATIONS - CORRECTION OF LANGUAGE

The State is to delete or modify language in state documents that refer to Alzheimer's disease or multi-infarct as "psychiatric disorders." These organic diseases have secondary behavioral manifestations which should be managed by an appropriate combination of medical, neurological, and psychiatric resources. [Maryland, p. IX-3]

REGULATIONS - ELIGIBILITY FOR WELFARE PROGRAMS

The State, in collaboration with Federal authorities, is to review the criteria for financial eligibility for assistance under the welfare programs (SSI, MA, AFDC, GPA), with a view to modifying excessively restrictive requirements that are damaging to families of ADRD victims forced to live below the poverty level. [Maryland, p. A-3]

REGULATIONS - ELIMINATING BIAS AGAINST WOMEN

The State is to review its Medical Assistance regulation and practices, with a view to eliminating a tilt that is particularly disadvantageous to female spouse caregivers. [Maryland, p. A-3]

RESPITE - ANNUAL VOUCHER

The State is to issue, subject to a reasonable means test, an annual voucher in the amount of $1500 to enable lower and middle income families of ADRD victims to purchase in-home respite or day care services. [Maryland, p. A-4]

RESPITE - INCENTIVES/MATCHING FUNDS

The State is to provide financial incentives or matching funds for respite services. Respite services are to include day care, in-home services and family counseling services. [(Prelim.) Kansas, p. 1]

RESPITE - REIMBURSEMENT

The State is to encourage hospitals and nursing homes to allow short-term respite stays by dementia patients. Incentives available to the state include adjustment of the reimbursement provisions for short-term stays. [Maryland, p. IX-2]

RESPITE - REIMBURSEMENT

The State is to encourage home health-care agencies to provide overnight respite stays. The State is also to provide standards for such care including assurance of appropriate training and reasonable reimbursement provisions. [Maryland, p. A-1]

RESPITE - STATE FUNDING

The respite care system of the Executive Office of Elder Affairs is to be expanded by 2 million dollars in FY1986. Respite services are to continue to include: homemaker/personal care companion, home health aides, skilled nursing, social day care, adult day health, and short-term institutional care. Services are to continue to be available on a sliding fee scale. [Massachusetts, p. 10]

RESPITE - SUBSIDIZED STIPEND PAYMENTS

The State is to train agency-based volunteer and stipended in-home respite and day-care workers. Families would contribute to the stipend, in whole or in part, as able, with backup by State and/or County funds. Professional positions are to be provided to recruit respite workers and maintain continuity. [Maryland, p. IX-2]

FINANCE RECOMMENDATIONS

ROLE OF PRIVATE INDUSTRY

Private industry, the state, health-care providers, and professionals should collaborate to bring about the programmatic changes outlined in the Committee's report. [Massachusetts, p. 13]

TAX ABATEMENT

The Legislature is to enact a state income tax abatement for those families carrying the financial burden of caring for patients with verified Alzheimer's Disease. [Rhode Island, p. 2]

TAX POLICY

Charges in tax policy, including credits, and mechanisms to protect family assets should be part of a comprehensive financing strategy. (Several current Federal bills would reform tax policy to assist families in financing care of the chronically disabled, including those suffering from Alzheimer's Disease. Other bills cited are Federal and State measures which would allow exemptions or deductions for a relative over 75, regardless of health needs.) [Massachusetts, p. 13]

EDUCATION RECOMMENDATIONS

EDUCATION - GENERAL PUBLIC/FAMILIES

A series of statewide forums are to be established to educate the general public and families of victims about all aspects of ADRD. [(Prelim.) Kansas, p. 2]

EDUCATION - HIGH SCHOOL STUDENTS

The Governor is to sponsor an annual contest for high school student projects and papers on dementia. [Maryland, p. A-3]

EDUCATION - POLICE

Continuing education and baccalaureate programs for the police are to contain substantial segments devoted to the sociology of the elderly. These segments are to include classes on dementia and existing community resources. [Rhode Island, p. 4]

EDUCATION - PROFESSIONALS

The Governo. is to exhort educational institutions and programs to include material on dementia in the curricula and examinations of professionals in medicine, nursing, pharmacy, associated health disciplines, social work, and law at undergraduate, graduate and postgraduate levels. The Board of Higher Education and health professionals' licensure and certification bodies are also to take appropriate action. [Maryland, p. IX-4]

EDUCATION - PROFESSIONALS

The Area Health Education Center program is to pursue all appropriate avenues for improving professional education in regard to ADRD. Activities are to include developing new continuing education programs, encouraging existing programs to include more information on ADRD and working with medical schools to expand the training of new physicians in the area of dementing illness. [Massachusetts, p. 16]

EDUCATION RECOMMENDATIONS

EDUCATION - SCHOOL CURRICULA

The State Department of Education and the Commission on Higher Education are to provide for course content at all school levels on aging and caring for the needs of the frail, poor, sick and elderly citizens. [Maryland, p. A-2]

EDUCATION - SCHOOL TEACHERS

The State is to require that teachers have continuing education updates on the subjects of normal aging and dementia. [Maryland, p. A-3]

EDUCATION - SPECIAL POPULATIONS

The State is to target education regarding ADRD to community institutions identified with special populations including Blacks, ethnic minorities and rural communities. [Maryland, p. A-3]

INFORMATION AND REFERRAL HELPLINE

A helpline for ADRD is to be developed through the State Dept. on Aging and and made available through the Area Agencies on Aging's existing Information and Referral Program. [(Prelim.) Kansas, p. 1]

INFORMATION AND REFERRAL TASK FORCE

A Special Task Force on Information and Referral (I&R) for ADRD is to be established for one year to evaluate and make recommendations for upgrading existing I&R services. The activities of the Task Force are to be coordinated by the (proposed) Office of Alzheimer's Information. [Massachusetts, p. 11]

INFORMATION CLEARINGHOUSE/HOTLINE/EDUCATION

The State is to contract with the Alzheimer's Disease and Related Disorders Association/Central Maryland to organize and manage: a statewide information clearinghouse which uses sites of Gateway I programs as distribution points; a statewide telephone hotline, coordinated with the local information and referral services of Gateway I; and, educational forums for the public and continuing education programs for health, legal and protective service workers. [Maryland, p. IX-5]

INFORMATION CLEARINGHOUSE - DIRECTORY OF RESOURCES

The proposed State contract with the Alzheimer's Disease and Related Disorders Association/Central Maryland for a clearinghouse is to include developing a directory of resources. [Maryland, p. A-2]

INFORMATION DISSEMINATION AGENCY

An Office of Alzheimer's Information is to be established within the Executive Office of Elder Affairs. The Office is to oversee and implement the recommendations of the (proposed) Special Task Force on Information and Referral for ADRD as well as working with the Area Health Education Center and the Long Term Care Work Group. The Office should have at least 3 staff members and a budget of at least $85,000/yr. [Massachusetts, p. 10]

INFORMATION DISSEMINATION

Regarding information dissemination, The Task Force found that: 1) the information offices of HHS and other Federal agencies should distribute all information materials on Alzheimer's Disease developed by each Federal program. 2) The Task Force should oversee the preparation of a pamphlet for practitioners and one for families, and 3) voluntary agencies are encouraged to assist in the process of disseminating information and developing new materials. [U.S. Dept. of H&HS, p. xiv]

PRIVATE CONTRIBUTIONS TO EDUCATION AND TRAINING

The State is to encourage private business firms to fund education and training in ADRD at college and professional levels. The State is also to encourage social, fraternal and religious organizations to participate in charitable, service and training functions related to ADRD. [Maryland, p. A-3]

TRAINING - LEGAL AND FINANCIAL COUNSELING

The State is to contract with the Alzheimer's Disease and Related Disorders Association to develop legal and financial counseling materials. The materials developed would be used by State, County and community agencies. [Maryland, p. IX-3]

TRAINING AIDES

The State Department of Health and Mental Hygiene is to add an instructional unit on dementia to its curriculum for training Geriatric Aides. An advisory committee is to participate in developing the material. [Maryland, p. IX-4]

TRAINING AIDES FOR OVERNIGHT IN-HOME RESPITE

The State is to encourage home health-care agencies to provide overnight respite stays. The State is also to provide standards for such care including assurance of appropriate training and reasonable reimbursement provisions. [Maryland, p. A-1]

TRAINING CAREGIVERS/HEALTH CARE PROVIDERS

Three multidisciplinary education and service demonstration centers are to be established for the benefit of patients afflicted with organic dementing illness and their families. Activities to include: diagnosis; counseling and referral; education/training of caregivers and providers; teaching and demonstration units in nursing homes and day care centers; preparing concise definitions of care for ADRD. [(Prelim.) Kansas, p. 2]

TRAINING FAMILIES - EMERGENCY SERVICES

The General Assembly is to call on all fire-rescue and health service units to educate families of the disabled elderly to use window stickers ("R") that indicate an incapacitated person is within the dwelling. [Maryland, p. A-3]

TRAINING FAMILIES/PROFESSIONAL PROVIDERS

The State is to provide grants to major educational institutions to develop training programs for the management of demented patients and to provide scholarships for trainees. Trainees would include family members and a full range of professional providers. [Maryland, p. IX-4]

TRAINING HEALTH PROFESSIONALS

The Area Health Education Center is to receive additional appropriations targeted for the training of health professionals in the area of ADRD. [Massachusetts, p. 11]

TRAINING HEALTH PROFESSIONALS - DIAGNOSIS/PATIENT MANAGEMENT

State Licensing Board examinations for medical, nursing and allied health professions are to include questions related to the recognition and differential diagnosis of the dementias and to the management of patients with dementia. [Massachusetts, p. 12]

TRAINING IN LONG-TERM CARE FACILITIES

The State Department of Health and Mental Hygiene is to include, in its licensure and certification regulations for long-term care facilities and programs, a requirement that in-service training include instruction on dementia and management of demented patients. [Maryland, p. IX-4]

TRAINING IN LONG-TERM CARE FACILITIES

The Department of Public Health is to be funded to develop education and training material for the appropriate in-house and attending staffs of long term care facilities in drug therapy and other management techniques for patients with ADRD. [Massachusetts, p. 11]

TRAINING INVESTIGATORS AND ACADEMIC LEADERS

Adequate training of investigators and academic leaders in all appropriate disciplines should be a high priority. (The Task Force was reviewing the findings and recommendations of the HHS Ad Hoc Committee on Enhancement of Training in Geriatrics and Gerontology at the time the Task Force report was prepared.) [U.S. Dept. of H&HS, p. xiv]

TRAINING PATHOLOGISTS

The Kansas Association of Pathologists are to research and develop optimal protocols to be used in postmortem examinations for confirming diagnoses of progressive degenerative organic dementias. These protocols are to be distributed to pathologists throughout the state with subsequent consideration of a brain registry. [(Prelim.) Kansas, p. 3]

TRAINING PHYSICIANS - DIAGNOSIS

Physicians are to use a protocol developed by a subcommittee of the Task Force for evaluation and diagnosis of demented patients. The protocol is to be disseminated through state and county-level Medical Societies. [(Prelim.) Kansas, p. 1]

TRAINING PHYSICIANS - DIAGNOSIS/PATIENT MANAGEMENT

The State is to enlist the Medical and Chirurgical (surgical) Faculty of Maryland to distribute materials to physicians on state-of-the art diagnosis and management of dementia. [Maryland, p. A-3]

TRAINING PHYSICIANS IN REPORTING CAUSE OF DEATH

The State is to conduct a campaign for improved death certificate reporting of ADRD. [Maryland, A-4]

TRAINING PROFESSIONALS/AIDES

The governing, licensing, certifying bodies of all professions are to assure basic and continuing education about ADRD. Respite/home-care sitters and all nurses aides are also to be appropriately educated. Areas of needed education include providing the safest and least restrictive environment and legal concerns. [(Prelim.) Kansas, p. 2]

TRAINING RESPITE AND DAY-CARE WORKERS

The State is to train agency-based volunteer and stipended in-home respite and day-care workers. Families would contribute to the stipend, in whole or in part, as able, with backup by State and/or County funds. Professional positions are to be provided to recruit respite workers and maintain continuity. [Maryland, p. IX-2]

CARE RECOMMENDATIONS

CARE - PRIORITY ASSIGNMENT

The State Department of Health and Mental Hygiene is to develop cooperative agreements with hospital and community health and mental health centers to provide care to ADRD patients as a service priority. [Maryland, p. A-2]

CARE DEMONSTRATION PROJECTS

The Long Term Care Work Group is to develop and recommend funding for at least four demonstration projects. These are to take different approaches to providing a coordinated, systematic, and creative

approach to serving the patients and families who suffer from ADRD. Funding is not to exceed $500,000/project. Either the Executive Office of Elder Affairs or of Human Services is to carry out actual program planning, funding and evaluation. [Massachusetts, p. 10]

CARE PROVIDERS - DEVELOPMENT

The State is to utilize the health planning process to encourage development of continuing care providers who will admit and meet the special needs of demented patients. [Maryland, p. A-2]

DIAGNOSIS - LONG-TERM CARE FACILITIES

The State is to require that all patients admitted to long-term care facilities be screened for cognitive impairment so that appropriate medical management can be initiated. [Maryland, p. A-1]

DIAGNOSIS - LONG-TERM CARE, DAY CARE, RESPITE FACILITIES

Long-term care facilities are to have full medical (including psychiatric) evaluations conducted before patients are admitted, or within 30 days of an emergency admission. Once admitted, patients suffering from ADRD are to be provided with specialized services delivered by appropriately trained staff. The same provisions are to apply to day-care centers and respite facilities as well. [Rhode Island, p. 5]

DIAGNOSIS CENTERS

Each Geriatric Evaluation Services unit is to have a dementia resource person included in the evaluation team or locally available. [Maryland, p. IX-3]

DIAGNOSIS CENTERS

The Legislature is to allocate funds for two proposed 20-bed diagnostic, service and research units. The Director of Mental Health, Retardation and Hospitals is then to activate the units. [Rhode Island, p. 4]

DIAGNOSIS CENTERS

The State is to establish three Geriatric Assessment Units for diagnostic screening purposes. [Rhode Island, p. 4]

DIAGNOSIS/COUNSELING AND REFERRAL/DEFINITIONS OF CARE

Three multidisciplinary education and service demonstration centers are to be established for the benefit of patients afflicted with organic dementing illness and their families. Activities to include: diagnosis; counseling and referral; education/training of caregivers and providers; teaching and demonstration units in nursing homes and day care centers; preparing concise definitions of care for ADRD. [(Prelim.) Kansas, p. 2]

FAMILY SUPPORT GROUPS - SELF-HELP

The State Office on Aging and the Alzheimer's Disease and Related Disorders Association are to work together to utilize local resources to replicate ADRD family support groups across the state. [Maryland, p. IX-3]

FAMILY SUPPORT GROUPS - THERAPEUTIC

County mental health units are to offer group therapy for family caregivers. [Maryland, p. A-2]

HOME-CENTERED CARE - DAY CARE

The State is to promote and provide support, by all means at its disposal, for increasing the capacity, geographic accessibility, and quality of day-care programs. [Maryland, pp. IX-2]

HOME-CENTERED CARE - DAY CARE/IN-HOME

The State is to sponsor day-care centers and respite programs in each of the major population centers. [Rhode Island, p. 2]

HOME-CENTERED CARE - DAY CARE/IN-HOME/FAMILY COUNSELING

The State is to provide financial incentives or matching funds for respite services. Respite services are to include day care, in-home services and family counseling services. [(Prelim.) Kansas, p. 1]

HOME CENTERED CARE - IN-HOME/DAY CARE

The State is to train agency-based volunteer and stipended in-home respite and day-care workers. Families would contribute to the stipend, in whole or in part, as able, with backup by State and/or County funds. Professional positions are to be provided to recruit respite workers and maintain continuity. [Maryland, p. IX-2]

HOME-CENTERED CARE - IN-HOME/DAY CARE/SHORT-TERM INSTITUTIONAL

The respite care system of the Executive Office of Elder Affairs is to be expanded by 2 million dollars in FY1986. Respite services are to continue to include: homemaker/personal care, companion, home health aides, skilled nursing, social day care, adult day health, and short-term institutional care. Services are to continue to be available on a sliding fee scale. [Massachusetts, p. 10]

HOME-CENTERED CARE - IN-HOME/HOME MANAGEMENT

The Executive Office Elder Affairs is to continue its efforts to improve the home-care system's capabilities to serve the most frail in the community setting, including Alzheimer's patients. This is to include training home-care staff and developing specialized programs, including home management services. [Massachusetts, p. 1.]

HOME-CENTERED CARE - IN-HOME/OVERNIGHT

The State is to encourage home health-care agencies to provide overnight respite stays. The State is also to provide standards for such care including assurance of appropriate training and reasonable reimbursement provisions. [Maryland, p. A-1]

HOME-CENTERED CARE - PATIENTS LIVING ALONE

The State is to allocate funds for the development of housing alternatives as an option for the demented, frail elderly who are living alone. The State is also to promulgate and enforce standards for these housing alternatives. [Maryland, p. A-1]

HOME-CENTERED CARE - PATIENTS WITHOUT SUPPORTIVE FAMILIES

The Executive Offices of Human Services and Elder Affairs are to ensure adequate provision of professional services in community settings. (There must be incentives to care for indigent Alzheimer's patients who lack supportive families.) [Massachusetts, p. 12]

HOME-CENTERED CARE - RESPITE

The Gateway II Project, "an economical as well as compassionate bulwark against otherwise publicly-funded institutionalization," is to be extended to all counties and more fully funded. The staffing of Geriatric Evaluation Services is to be increased to work effectively with Gateway II. [Maryland, p. IX-5]

HOME-CENTERED CARE - SHORT-TERM INSTITUTIONAL RESPITE

The State is to encourage hospitals and nursing homes to allow short-term respite stays by dementia patients. Incentives available to the state include adjustment of the reimbursement provisions for short-term stays. [Maryland, p. IX-2]

HOME-CENTERED CARE - TRANSPORTATION TO DAY CARE

The State is to promote the provision of transportation as a part of day-care programs. [Maryland, p. A-1]

HOME-CENTERED CARE - TRANSPORTATION TO MEDICAL CARE

The State Medicaid agency is to ensure the availability of transportation, under Federal law, to necessary medical care. [Maryland, p. A-4]

LEGAL ISSUES - CARE DECISIONS

The Governor is to appoint a commission or committee to deal with legal issues of great concern to patients with ADRD, including: distribution of property and burden of care, trusts, guardianships, conservatorships, durable powers of attorney, living wills, the patient as research subject, family participation in medical care and the administration of psychotropic medication and the jurisdiction of the courts. [Massachusetts, p. 12]

LEGAL ISSUES IN CARE - GUARDIANSHIP

The State is to establish an Office of Public Guardianship. (It is difficult, under current Rhode Island regulations, to obtain a guardian if the patient has limited financial means.) The State is also to explore the possibility of a statewide Probate Court system. The State is also to establish a permanent Code Commission for the Impaired Elderly. [Rhode Island, p. 4]

LONG-TERM CARE - NURSING HOME STANDARDS

The State is to incorporate in its programs of nursing home inspections, standards for procedures in the management of behavioral problems among demented patients. [Maryland, p. A-1]

MENTAL HEALTH CARE - PSYCHIATRIC TREATMENT

The State is to modify its Medicaid reimbursement policy to appropriately support psychiatric consultations for the treatment of behavioral disturbances secondary to dementia for Medicaid patients in nursing homes. [Maryland, p. A-2]

MENTAL HEALTH CARE - COMMUNITY MENTAL HEALTH CENTERS

The State is to hold Community Mental Health Centers responsible for serving the elderly and the demented among them who manifest secondary behavior disturbances. [Maryland, p. A-2]

RESEARCH RECOMMENDATIONS

CARE DECISIONS - CURRENT INSTITUTIONAL POLICIES

The State is to investigate nursing home practices regarding admitting and retaining ADRD patients. The State is also to investigate the appropriateness of standards used by Geriatric Evaluation Services and Professional Review Organization in determining the level of institutional care required for ADRD patients. [Maryland, p. A-1]

CARE SYSTEMS

Promising directions for research on systems of care are: 1) study the range of community and institutional services relevant to Alzheimer's disease patients, and 2) sponsor conferences and workshops with broad dissemination of proceedings. [U.S. Dept. of H&HS, p. xiii]

CLEARINGHOUSE - INFORMATION ON CURRENT RESEARCH

The proposed State contract with the Alzheimer's Disease and Related Disorders Association/Central Maryland for a clearinghouse is to include a system for sharing information on current research on dementia being conducted in the State. [Maryland, p. A-4]

CLEARINGHOUSE - STATE RESOURCE CENTER

An existing medical school library is to be designated as a resource center to collect and disseminate all current scientific data. [(Prelim.) Kansas, p. 2]

CLINICAL COURSE

Promising directions for research on clinical course are: 1) develop longitudinal assessment instruments capable of reliably measuring behavioral and biological changes over time, 2) investigate factors that hasten or delay the progression of symptomatology, and 3) examine individual differences and variability in severity, rate of deterioration, duration of illness, and capacity for self-care. [U.S. Dept. of H&HS, p. xii]

DIAGNOSIS

Promising directions for research on diagnosis are: 1) develop international standardized diagnostic research criteria, 2) develop biological and/or behavioral markers for early detection, 3) undertake longitudinal studies in order to document the progression of the disease, and 4) examine cases of serious discrepancy between cognitive deficit and brain impairment. [U.S. Dept. of H&HS, p. xii]

DIAGNOSIS/BRAIN REGISTRY

The Kansas Association of Pathologists are to research and develop optimal protocols to be used in postmortem examinations for confirming diagnoses of progressive degenerative organic dementias. These protocols are to be distributed to pathologists throughout the state with subsequent consideration of a brain registry. [(Prelim.) Kansas, p. 3]

EPIDEMIOLOGY

Promising directions for future research on epidemiology are: 1) develop standardized diagnostic assessments that are suitable for field use, 2) determine age-specific incidence and prevalence rates, and 3) assess a variety of possible risk factors. [U.S. Dept. of H&HS, p. xi]

EPIDEMIOLOGY - DEATH CERTIFICATE REPORTING

The State is to conduct a campaign for improved death certificate reporting of ADRD. [Maryland A-4]

EPIDEMIOLOGY - REGISTRY OF ADRD CASES

The State Department of Health and Mental Hygiene is to maintain a registry of ADRD cases. [Maryland, p. A-4]

EPIDEMIOLOGY/DEMOGRAPHIC/HEALTH SERVICES

In order to assure wise use of its resources, the State is to promote the development of demographic, epidemiologic and health services data on dementia. [Maryland, p. IX-7]

EPIDEMIOLOGY/EXTENT OF CARE RECEIVED

Funds are to be appropriated for the Department of Public Health to conduct a health interview survey to determine the number of patients in the Commonwealth with Alzheimer's Disease, their family status, their utilization of resources, and their ability to gain access to the health care system. [Massachusetts, p. 10]

ETIOLOGY AND PATHOGENESIS

Promising directions for research on etiology and pathogenisis are: 1) enhance understanding of the cause(s), 2) encourage existing brain tissue banks to include tissue from Alzheimer's Disease patients and age-matched controls, and 3) develop animal models of Alzheimer's disease with more precise neuropathologic and biochemical correlates. [U.S. Dept. of H&HS, p. xii]

FAMILY

Promising directions for research on the family are: 1) evaluate factors that aid the family in early recognition of the symptoms and in care decisions, 2) identify the most effective coping strategies and interventions, and 3) explore innovative social support systems for patients who do not have family assistance. [U.S. Dept. of H&HS, p. xiii]

RESEARCH FUNDING

The Commission appeals to those who dispense research funds as well as those who undertake research to look to the dementias of the elderly as the next epidemic to conquer. [Rhode Island, p. 5]

RESEARCH FUNDING - FEDERAL

The State is to lobby for far greater Federal support of research on ADRD. [Maryland, p. A-4]

TREATMENT

Promising directions for research on treatment are: 1) develop new treatment agents, 2) develop new experimental animal models, 3) establish more sensitive measures of cognition, etc., 4) develop psychotherapy modalities, 5) evaluate the influence of the environment, 6) study the efficacy of support and self-help groups, 7) determine the impact of teaching behavioral management to caregivers, and 8) evaluate which patient behaviors [U.S. Dept. of H&HS, p. xii]

COORDINATION RECOMMENDATIONS

INTER-DEPARTMENTAL LONG TERM CARE COMMISSION

Kansas House Concurrent Resolution 5015 is to be passed with an amendment to include all patients with ADRD. (This directs the Secretaries of Aging, KDHE and SRS to jointly develop a Long Term Care Commission.) [(Prelim.) Kansas, p. 3]

ROLE OF COMMUNITY MENTAL HEALTH CENTERS

The State is to hold Community Mental Health Centers responsible for serving the elderly and the demented among them who manifest secondary behavior disturbances. [Maryland, p. A-2]

ROLE OF PRIVATE SECTOR ADVOCATES

To ensure the recommendations of the Committee are brought to fruition, advocates must continue to actively work with the state government to achieve their goals. [Massachusetts, p. 13]

STATE AGENCY

The Governor's Council on Mental Health is to be assigned the coordination and implementation of the recommendations of the Commission. The Alzheimer's Disease and Related Disorders Association - Rhode Island Chapter is to serve as an advisory body to the Council. [Rhode Island, p. 5]

STATE AGENCY FOR NON-MEDICAL SERVICES

The State is to consolidate non-medical services for the impaired elderly in a specific division of the Department of Elderly Affairs. [Rhode Island, p. 3]

STATE AGENCY TO MONITOR PROGRESS

The Governor is to charge a State agency with coordinating and monitoring progress on the recommendations of the Task Force on Alzheimer's Disease and Related Disorders. [Maryland, IX-7]

STATE COMMITMENT TO PROVIDE ASSISTANCE

The State is to provide assistance until such time as research renders Alzheimer's Disease manageable. During the past century the State has repeatedly recognized that certain diseases impose excessive burdens upon the private citizen, threatened the health of the community and require active state intervention. During the 19th century the State constructed special facilities for contagious diseases; and in the 20th century, sanitaria for tuberculosis and schizophrenia. [Rhode Island, p. 2]

STATE RECOGNITION OF THE PROBLEM

The executive and legislative leadership are to come to terms with the social enormity of this problem which affects close to 1% of the population of the State. The State is to commit sufficient resources for the identification and continuing care of its citizens with Alzheimer's Disease. [Rhode Island, p. 2]

SUPPORT FOR ROYBAL CARE BILL

A statement of support for the proposed federal legislation, Rep. Roybal's CARE bill (Comprehensive Alzheimer's Assistance, Research and Education Act of 1985), should be passed by the end of the 1986 (State) legislative session. [(Prelim.) Kansas, p. 3]

YOUNGER PATIENTS - AGENCY RESPONSIBILITY

The Older Kansans Senior Care Act HB 2491 is to be passed with amendments to delete the age restriction and to include specific categories of functionally impaired adults such as Alzheimer's victims. [(Prelim.) Kansas, p. 3]

YOUNGER PATIENTS - AGENCY RESPONSIBILITY

The State is to give the Geriatric Evaluation Services latitude and funding to evaluate individuals under 60 when dementia is or may be a differential diagnosis. [Maryland, p. A-1]

YOUNGER PATIENTS - AGENCY RESPONSIBILITY

The Executive Office of Human Services, through its Department of Social Services, is to organize and provide services to Alzheimer's patients under 60 years of age. (The Executive Office of Elder Affairs is mandated to provide service to individuals aged 60 and over.) [Massachusetts, p. 12]

SUMMARY

Finance

The 39 recommendations related to financing had two major themes:

- assistance to families so they can continue home-care for as long as possible; and
- insurance proposals for covering the cost of long-term care of ADRD patients.

The recommendations covered such diverse areas as: legal issues affecting family financing; mandated provision of long-term care insurance, retroactive determination of eligibility for disability benefits when a long time passes between loss of employment and diagnosis of ADRD, changes in regulation language, direct payments to caregivers, and tax benefits for caregivers.

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Education

The 32 recommendations in this section addressed three principle concerns:

- job-specific training for health workers;
- general education; and
- providing access to existing information.

Recommendations also mentioned training families and non-health professionals and private funding of educational programs.

Care

The 29 recommendations in this section have two major themes:

- providing a full-spectrum of respite care services to support home caregivers; and
- expanding the availability and quality of diagnostic services.

Other areas mentioned are: family support groups, legal issues, mental health care, long-term care and general comments on the importance of providing care.

Research

These 17 recommendations most frequently dealt with epidemiology. Lack of reliable data on the incidence of the disease was presented as a barrier to effective planning and delivery of services. Nearly half the recommendations in this section are from the report of the Secretary's Task Force, which focused on "promising directions for future research."

Coordination

The 12 recommendations found in this section focused on:

- establishing state agencies to provide coordination and oversee the implementation on the task force/commission recommendations.

Other areas addressed are: different approaches to younger ADRD patients, the role of various actors in the public scene, the leadership role to be taken by state governments, and endorsement of federal coordinating legislation.)

APPENDIX

SOURCES

Task Force on Alzheimer's Disease and Related Disorders. Maryland Report on Alzheimer's Disease and Related Disorders. Baltimore: Executive Department, 1985.

Governor's Committee on Alzheimer's Disease. Executive Summary. Springfield, Massachusetts: The Commonwealth of Massachusetts, 1985.

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Secretary's Task Force on Alzheimer's Disease. Alzheimer's Disease. Washington, D.C.: U.S. Department of Health and Human Services, 1984.

Kansas Alzheimer's and Related Diseases Task Force. Summary Report (Preliminary). Topeka, Kansas: Department of Aging, 1985.

FURTHER RESEARCH

The goal of the author is to maintain a current database of recommendations of public task forces and commissions on ADRD. Readers are invited to participate in this on-going work.

If you obtain a new report, send it to me. If you would like to receive up-dated listings, write and let me know. If you have comments on the presentation of information in this paper, they would be most welcome.

Thank you for your own commitment to the conquest of Alzheimer's Disease and related disorders.

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A A H A

April 23, 1986

The Honorable Edward R. Roybal
Chairman
House Select Committee on Aging
House Annex I, Room 712
Washington, D.C. 20515

Dear Chairman Roybal:

The American Association of Homes for the Aging commends your continued efforts to provide relief for the burden borne by the victims of Alzheimer's Disease and their families by addressing the ever-increasing need for concerted national action in your April 11th hearing, "Setting a Federal Agenda for Alzheimer's Disease," held in Detroit Michigan. As an Association representing approximately 2800 non-profit providers of housing, health care, long term care, and community services for the elderly, AAHA remains keenly aware of the vast amounts of time and skill which are invested by both family caregivers and the broad range of health care professionals involved in providing quality care to these individuals. To complement and support these efforts, federal funding is needed for research to continue to improve diagnostic tools and treatment, as well as for family-support initiatives such as respite care, and resource information and education.

AAHA is pleased to have the opportunity to submit a statement for the record in conjunction with the April 11th hearing. This statement presents AAHA's views with regard to public policy decision making and reinforces the Association's identification of Alzheimer's Disease as a priority issue to the nation.

Thank you again for your attention to this most important issue.

Sincerely,

Sheldon L. Goldberg
Executive Vice President

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William R. Thaver, *President* ● Sheldon L. Goldberg, *Executive Vice President*

STATEMEMT BY THE AMERICAN ASSOCIATION OF HOMES FOR THE AGING

Mr. Chairman and members of the Committee, the American Association of Homes for the Aging appreciates the opportunity to submit testimony expressing to the ever-increasing need for concerted and cooperative action on behalf of the victims of Alzheimer's Disease. AAHA commends the Committee for its continued efforts and diligence in securing the necessary funds and accompanying supportive services required by Alzheimer's patients and their families.

AAHA is a national organization representing approximately 2,800 non-profit facilities which provide housing, health care, and community services daily to more than 500,000 elderly individuals throughout the United States. Over 75% of AAHA members are affiliated with religious organizations. The remaining members are sponsored by private foundations, government agencies, unions, fraternal organizations, and community groups.

Many of AAHA's member facilities have developed specialized Alzheimer's programs, including adult day care, long term and respite care, and the facilitation of family support group meetings, in order to respond to the service needs of to the victims of Alzheimer's disease and their families.

The Adult Day Health Services of the Handmaker Jewish Geriatric Center, Tuscon, Arizona, has developed a comprehensive program of services for persons being cared for at home, offering respite and a supportive environment to care-givers and patients. The full program includes health surveillance; speech; occupational; and music therapy; individual and group counseling; training in activities of daily living; educational, recreational and leisure activities as well as nutritional guidance and a hot noon meal. Adult Day Health Services currently serves more than 500 people out of two centers, including a protective care unit which specifically addresses the needs of Alzheimer's and related disorders participants. In addition to the full gamut of day health activities, the protective care unit offers activities such as reality games which include the identification of objects, sounds, smells, and tastes, and the recollection of names, places, and past events. These activities concentrate on and encourage maintenance of individual abilities, while, at the same time, recognize individual limitations.

The Morningside House Nursing Home Company, Inc. Bronx, NY is a 386-bed facility which includes two in-house units focused primarily on the care of residents with Alzheimer's Disease. Morningside House has responded to the broad range in functioning levels of patients suffering from Alzheimer's

Disease and related disorders through development and implementation of a Comprehensive Mental Health Treatment Program. The program incorporates a seven-branch system of therapy including family support groups, group therapy with the severely impaired; physical exercise in a variety of forms; and, for higher functioning patients, reminiscence therapy which involves life recollection up to, and including, admission to the nursing home. The program also consists of skills training which stresses compensation for skills lost; orientation which incorporates a "buddy system" for mild to moderately impaired residents; and support therapy groups conducted on levels which respond to patients' specific needs and functioning, such as difficulty or inability to articulate. Morningside House has also implemented environmental and dietary modifications such as the inclusion of more finger foods and specifically designed eating utensils, which enhance and encourage optimal functioning for Alzheimer's patients in this fundamental activity of daily life.
The above descriptions represent only two examples of the many excellent and innovative programs which have been initiated within the voluntary sector and which need public support in order to continue to benefit the rising number of Alzheimer's victims and their families.

The American Association of Homes for the Aging is representative for both institutional and non-institutional providers of care for the elderly, would like to take this opportunity to reiterate its support for H.R. 2280, the Comprehensive Alzheimer's Assistance Research and Education Act of 1985 (CARE). CARE responds to the needs of Alzheimer's victims and their families by seeking to provide increased funds and avenues for the advancement of research and the coordination of programs and services, and establish cooperative efforts between the States and the Federal Government to develop services and policies.

AAHA particularly commends CARE and the Committee's continued examination of the roles of Medicare and Medicaid in covering nursing home care, respite, and home health care. The cost of caring for victims of Alzheimer's Disease, in terms of both investment of time and real dollars increases steadily as the degenerative progression of the disease advances. This often occurs over a period of 7-12 years. The increasing need for constant supervision and surveillance, due to accelerating episodes of inappropriate, unpredictable, or possibly dangerous behaviors, places a heavy burden on the family caregiver. Frequently, caregivers are the spouses, who are elderly themselves. As the disease advances, there is an accompanying progression in the demand for health and health related services. A pilot study recently cited in "Gerontologist," estimated the costs involved in home care for an elderly person suffering from Senile Dementia, to be approximately $11,735 per year. AAHA supports the

expansion of the Medicare and Medicaid programs to include coverage for services designed to allow maintenance of the patient at home for as long as possible.

AAHA also recognizes that almost all Alzheimer's victims will require nursing home placement at some point, even with the availability of at home support services, due to the absence of family caregivers or when care needs extend beyond the family caregiver's capacities. However, Medicaid and Medicare reimbursement for nursing home care, whether based on a case mix system or an ICF/SNF level of care distinction is particularly inadequate for Alzheimer's patients, as they tend to demonstrate deceptively low care level needs. Due to the high degree of involvement required by staff in direct care behaviors with these patients, caring for Alzheimer's patients is labor intensive and thus costly, even when the need for skilled services is low.

Current Medicare policy often precludes coverage for victims of Alzheimer's Disease because skilled services may not be required and there exists limited "rehabilitative" potential in the acute care sense. This represents to AAHA a dramatic example of the need for better understanding of the concept of rehabilitation in the context of long term care. For Alzheimer's victims and other chronically impaired elderly, rehabilitation should mean using therapies directed toward maintaining existing functioning levels or compensating for skills lost; success is to enhance both independence and individual dignity for as long as possible, as this is integral to providing optimal quality of care and consequently, ensuring optimal quality of life. While current Medicaid policy does provide nursing home coverage for poor elderly reimbursement also proves to be inadequate due to the nature of the care needs of Alzheimer's patients as described above.

AAHA supports a review and modification of public reimbursement and regulatory policies and procedures to accommodate the need for respite care. Again, for caregivers whose capacities have been overextended, the availability of respite care can provide a period of relief which, in conjunction with other community support systems, will ultimately allow the patient to remain at home for a longer period of time. Respite care may also provide an avenue for ensuring optimal quality of care while Alzheimer's victims await long term placement in a nursing home. Other benefits afforded through the use of respite care are the opportunities to evaluate both the patient's and the family's response to placement, an invaluable tool to providers in anticipating the therapies and support services which will prove beneficial at the point long term care is required.

Educating the public about Alzheimer's Disease and providing assistance in accessing information and services to families of Alzheimer's victims, both components of CARE's National Education Program, are also areas supported strongly by AAHA. The Association has heard repeatedly through its members that the most critical problem facing families of Alzheimer's patients is the difficulty in accessing information. Information needs to be made available on issues such as the nature of the disease, research findings, public and private insurance programs, service options, and how to find a physician or medical center that provides access to comprehensive diagnosis and assessment. AAHA commends the effort to establish a Central Information Clearinghouse and suggests further the development of a national or state level resource directory listing programs, services, organizations, and agencies serving Alzheimer's victims and their families. The accompanying implementation of a national or state level toll-free hotline would enhance the directory's use as a referral resource to both health care providers and the general public.

AAHA also continues to recognize the need to disseminate information to our members, as well as to the community. In 1984, the Association called for the development of an Alzheimer's Network to provide a central vehicle for the sharing of information and resources. The Network, comprised of nearly 100 representatives of AAHA member facilities, views 1986 as a planning year for the facilitation of activities leading to goals which include the compilation of an AAHA resource directory listing both institutional and non-institutional programs serving Alzheimer's victims and their families. Also, to address concerns expressed by AAHA members, proposed network activities include the provision of technical assistance to members in their respective states in developing Alzheimer's programs and services, the facilitation of support groups serving families and/or professional caregivers, the facilitation of advocacy groups to represent Alzheimer's victims and their families before state legislatures, and assistance in the development of a hotline, viewed as integral to the dissemination of specific resource information on a state level.

Most recently, AAHA appointed a Member Task Force on Alzheimer's Disease to work with the Association on determining how it can best serve the needs of members and facilities caring for Alzheimer's patients. This task force will work to charter a course for Alzheimer's activities in the Association in 1986 and future years. The Task Force has identified as priorities the care of Alzheimer's victims in nursing homes and communities for older Americans,

emphasizing AAHA's commitment to the provision of the highest quality of care for these individuals. AAHA's Task Force and would welcome the opportunity to meet with the Committee at any time for further discussion of these issues.

Federal support for geriatric training in medical schools, with career teacher incentives as well as research incentives, is one aspect of the need for continued and more specialized education that AAHA views as integral to the diagnosis, treatment, and management of Alzheimer's Disease and related disorders. Joint Federal and state efforts to provide ongoing educational and training services for the broad range of health care and long term professionals, involved in the provision of services to Alzheimer's patients and their families is also critical to the treatment and accurate dissemination of clinical information.

Finally, the Committee's commitment to the advancement of research into the cause, prevention, anhd treatment of Alzheimer's Disease and related disorders through extension of the current Research Center Program is commended by AAHA. The Association is aware of the effects that funding cuts and deficit reduction actions have had, and can have, on the maintenance and expansion of this program. We do feel however, that it is important for Congress to demonstrate its recognition of Alzheimer's Disease as a priority issue, and to support the 2.5 million Americans currently suffering from this disease, by assuring no further reductions in the commitment levels sustained for the previous year.

AAHA believes that voluntary agencies play a vital role in the initiation and provision of services to the elderly, and especially to the victims of Alzheimer's Disease and related disorders, but, that the Federal Government also has a key role to play in responding to the needs of the aging in our society. We will continue to support the efforts of this Committee in securing the necessary funding for these Alzheimer's programs and initiative.

STATEMENT OF SHARON BALASKO

My name is Sharon Balasko, 1084 E. Grand Blanc Rd. Grand Blanc, Michigan 48439.

I am a active member of ADRDA-Flint area and secretary of the morning group. I will give my comments and observations on the behalf of my parents, my father, the victim of a dementia disease and my mother, his care giver. Dad is beyond the worry of his disease, mother has the emotional, physical and financial burden, the worry of losing her husband of 55 years, the physical burden of caring for him alone, at home during the first years of his illness and now the financial worry about the money lasting for his care, and about what will be left for her care when he is gone. Like many women of her age, she has no pension just Social Security.

My father, a retired auto worker(for 36years), was a good citizen, paid his taxes, obeyed the laws of society, saved a little money for retirement for my mother and himself and then this catastrophic illness hit him.

Mother took care of him for the first 5-6 years after his diagnosis. Then 5 years ago his illness took an acute turn for the worse. Suddenly he was like a vegatable, unable to do anything for his own care, able to do less than a new born babe. Unable to scratch his nose, unable to feed himself or walk or turn over, unable to move his own bowels. It was devastating to our small family. Mother could no longer care for him at home, alone. We tried to get him home care. It would cost over $3000.00 a month for reliable care to care for him properly, the way he deserved. Mom couldn't afford that kind of money. Dad is considered a BASIC care patient. She would get little help. He didn't sleep well so she couldn't get any rest day or night. We had no choice, We would have preferred to keep him home but we had to put him in a nursing home. We had no way of washing him except for basin bathes. We couldn't get him to his doctor except in an ambulance.

The nursing home we picked was one of the best in the area. Would you believe they didn't have a wheelchair for dad and Blue Cross-Medicare wouldn't pay for one once he was in the nursing home. Not until dad fell out of a geriatric chair did the home find one for him.

Dads room at the home started out 4 years ago at $40.00 a day. It is now $53.00 a day. Everytime Social Security is raised a few dollars, dads room is raised $2.00 a day ($60.00 a month), putting them more in the hole everytime.

My mothers health is failing because of the enormous emotional, physical and financial strain of my dads illness.

Mom is living on a small amount of money. She won't buy herself anything and isn't eating properly, has stomach trouble because she worries about whether or not there's going to be enough money for dads care.

The nursing home is under staffed, the turn over of help is great, the pay very low, mostly minimum wage.

We go and feed dad everyday, both meals, because one nurses aid may have 6-10 patients to feed, less than 10 minutes a patient. How would you like to eat every meal, everyday in 10 minutes? Needless to say everything isn't fed. The trays are usually incorrect- tea instead of coffee - no salt, no butter, no milk ect. If you are on a pureed diet (a patient with dementia can't keep their dentures in their mouth) you will get a little white puree (meat) a little green (veg.) if salad is on the menu, the patient gets nothing.

I believe it should be law that applesauce, cottage cheese be subsituted. The food is unappetizing. This is why mom and I oversee dads meals. I kept a diary of dads meals for a month, the trays were never once correct. What about the poor patients that have no one to check on them?

And for this we pay $20,000.00 a year. Dad had a life sentence, a room he shares and his family does his laundry.

The criminal gets his free, plus color T.V.,a single cell, maybe some education etc..

We have a stack of Blue Cross - Medicare statements, unnessary lab work is done weekly. The house doctor who calls weekly is unnessesary.It would have been cheaper for medicare-Blue Cross to help with home care than at the nursing home.

Financial help, support services are nessessary so patients can be cared for in their home even if they are BASIC care. Changes are needed in medicade so the remaining spouse isn't impoverished. My mother shouldn't have to worry about poverty at her age.

Nursing homes should be better staffed, the staff more informed, strickter protection for the patients, better nutrition for all including those on pureed diets, and wheel chairs available. House doctors shouldn't have a financial interest in the nursing home or lab.

My father should get superior care for $20,000.00 a year, and we should be confident that his care and nutrition is complete if I am unable to check on it.

A devoted daughter who is losing both parents

Sincerely
Sharon Balasko

TESTIMONY (April 11, 1986)

My name is Robert W. Bowman of Ann Arbor, Michigan. I am 71 years of age, a professional engineer licensed in Michigan conducting a private consulting practice. I am the caregiver for my wife of 45 years of age 69, who was diagnosed as having Alzheimer's disease following exhaustive tests in October 1984. Following this diagnosis, I resigned a full time position in an architectural-engineering firm to be an active caregiver.

I am a member of the Board of Directors of the ADRDA-Greater Ann Arbor Chapter which encompasses nine counties and am active in a support group meeting in Ann Arbor. In these activities I am in contact with many caregivers and individuals affected by the emotional, physical and econpmic devastation of Alzheimer's disease. However my comments are on behalf of my family and myself.

My wife is best described as being in the middle stages of this debilitating disease. Although she has been told she has Alzheimer's disease she has little recall and concern about her condition. She is incapable of preparing meals and needs to be coached in countless simple tasks. Based on scientific measurement in the past year she has lost 50% of her communication skills.

At present she can be left alone for up to two hours in mid-morning, mid-afternoun or early evening. However to be away for a greater period of time I engage home care individuals to stay with her. The cost of this service is approximately $6.00 per hour. Fortunately in the Ann Arbor area home care services are available. In many areas I understand such caregiver service is either non-existent or not readily available.

But what is ahead?

It appears that most caregivers would prefer to keep the Alzheimer's patient in the familiar home environment as long as the caring is at a manageable level. This of course keeps costs lower and is usually most desireable for the patient. We intend to follow this course. There is a need for economic relief to the to the family using these type of services.

My situation at present is not difficult but as I see the trauma of other care givers I am concerned for the future.

Much needs to be done to alleviate the suffering of a physical,emotional and economic nature arising from this unrelenting disease.

Thank you for your attention.

PREPARED STATEMENT OF BARBARA J. BRINK, MEMBER-AT-LARGE, BOARD OF DIRECTORS, ALLEGAN-OTTAWA AFFILIATE, ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION (ADRDA). 721 LUGERS RD., HOLLAND, MI.

My name is Barbara Brink. I am a Member-At-Large of the Board of Directors, Allegan-Ottawa Affiliate, Alzheimer's Disease and Related Disorders Association which meets at Evergreen Commons Senior Center, 480 State Street, Holland, Michigan, 49423. I am writing on behalf of myself, a daughter and only child of an Alzheimer's victim who died Sept. 6, 1985.

The symptons of Alzheimer's disease were noticeable on my mother six years prior to her death. She lived at home with my father for four of those years until my father was told by his physician that he should no longer let the stress and responsibility of caring for my mother adversely affect his health. I was assisting him with my mother's personal chores. I was also the mother of four teenagers.

The thought of putting my mother in a nursing home distressed us greatly. My parents had worked hard togetner to achieve what they had. My mother enjoyed her home very much and as her disease symptons increased it was the only place where she felt secure and comfortable.

In past years my mother had cared for my father's mother, a stroke patient for five years while living with them. She and her sisters had also cared for their parents in their home until they died there. My wish was that I could do as much for my mother. I investigated the possibility of in-home care and found the cost to be $70.00 per day while the nursing home fee was $45-$50 per day. The only choice feasible seemed to be the nursing home. My parents did not qualify for Medicaid and Medicare did not cover custodial care.

As my mother gradually lost her memory and ability to function normally she depended on my father greatly for security. The day we took her to the nrusing home and she realized that she and my father would be separated was the most traumatic day of our lives. My father says that Alzheimer's disease is worse than death and I agree with him. I have wished that while my mother was still cognizant of her surroundings we could have kept her at home another year with the assistance of in-home care. We really do want to care for our loved ones but with such a devasting disease as Alzheimer's few families can do it alone.

My father paid the cost of nursing home care for two years and he said that he was proud of having done so. But what about those people who have been patients in nursing homes for ten years or more? I have seen some of them! My experience with Alzheimer's disease has made me concerned for those families who may yet have to face it in the future. They need assistance in caring and you can help them.

I urge your committee to take the lead in passing the Comprehensive Alzheimer's Assistance, Research and Education Act of 1985 (CARE).

April 8, 1986

Select Committee on Aging
U.S. House of Representatives
Washington D.C. 20515

Testimony on cost of Alzheimer's Disease to families

This testimony is addressed to the financial cost entailed for a family over a period of only 5½ years. Emotional stress and physical fatigue are harder to put a dollar sign on.

Most devastating and quite incalculable is the fact that the husband and breadwinner in this family lost his job as a result of Alzheimer's Disease just 1½ years short of qualifying for retirement benefits. We suffered the loss of all pensions at a time when the family could least afford to endure this burden.

Because of the income loss and the obvious inability to qualify for unemployment benefits, the family sought a disability award from Social Security. After two denials on the basis that the husband "was not disabled", it became necessary for the family to engage a lawyer to help with appeals. In addition to the cost of the attorney's fees of $1200.00, the spouse lost work time assembling further documentation and keeping appointments. When the award finally was made, the benefits were quite reduced because the husband happened to be born in 1919, one of the "notch years" in which the administration made mathematical errors in computing the benefits to which persons in these years should be entitled. Over a year had passed before benefits were finally awarded.

The husband was treated during the early stages of the disease at Lafayette Clinic in Detroit. Although the treatment was offered free, transportation and work time lost for the spouse amounted to $1000.00.

With more mental deterioration in husband's condition, it became necessary for spouse to apply to Probate Court for Guardianship and Conservatorship. The court-appointed guardian ad litem and other court fees and lost work time cost $400.00.

As the future loomed ever more hopeless in terms of providing for the inevitable full time nursing care, the spouse was forced into divorce action to protect her own modest earnings and a small IRA fund for her own needs in later years. Cost for this was $1000,00.

To allow the spouse to continue working, day care had to be found for the husband. Two days a week was all they could afford. This cost amounted to over $2,000.00 during this time.

In order to survive financially and help their son with college costs, it was necessary to borrow the full limit on all insurance policies held by both spouses. The cost of maintaining the premiums and pay the interest due on the loans is $6,000.00 to date and will continue ad infinitum as the family will never be able to repay the principal on these loans.

Very occasional respite care for the wife during this period of time amounted to $500.00, a modest enough cost for the stress burden of the care-giver.

This statement shows a minimum of $12,100 cost borne by the family which still does not include any amount for the fact that the family lost all retirement benefits because of the onset of this condition at age 60½. At present the husband resides at Michigan Veteran's Facility at a cost of $1615.00 per month. His combined small veteran's pension and aforementioned reduced Social Security benefit do not cover this amount.

STATEMENT OF LENORE K. FRONTCZAK

Member of Detroit Chapter of Alzheimer's and Related Disorders Association
April 8, 1986

Lenore K. Frontczak

STATEMENT OF DEBIRAH A. GERBASI, DETROIT, MI

I am an active member of the Board of Directors of ADRDA-Detroit Area Chapter and a family member as my grandmother was suspected to have had Alzheimer's Disease. The comments I am about to make are my own.

Initially, I am compelled to state that although I will refer continually to Alzheimer's Disease (A.D.), the certainty of the diagnosis during the life of the patient is an educated guess at best. This diagnosis can only be confirmed by an autopsy. Many other dementia patients go undiagnosed or misdiagnosed and the symptoms and management are quite similar. Therefore, I take the liberty of including them in my thoughts.

Care of the Alzheimer's patient can be financially, physically and emotionally devastating. However, the greater majority of Alzheimer's families prefer extending home care as long as humanly possible.

From personal experience, I can attest that the A.D. caregiver is a unique individual. They are called upon to respond selflessly to their loved one's physical and emotional needs. Many times these needs become demands. Many times these demands become emotionally draining and/or physically abusive. For example: The A.D. patient very often has no concept of time. Frequently they become agitated and/or restless at night. They may wander or or shout "All Night LONG". The caregiver in fear of their wandering out, turning on the stove, turning off the furnace etc., must stay awake with them. Even in the case of the bedridden Alzheimer's patient, night agitation is frequently present. Although the fear of "wandering" is not paramount the caregiver, out of love and concern, sits up desperately trying to calm them and ease the seemingly unbearable emotional pain being endured by the patient. This type of continuous care drains the caregiver both physically and emotionally. The pace is such that many sacrifice their health to the rigors of the task.

The stress of Alzheimer's Disease on the family unit is tremendous. Many times other family members in the household feel the loss of the caregiver in their lives. Many times there is resentment. Many more times, there is guilt.

Some families choose to bring in home health aids in conjunction with a visiting nurse to help with the physical burden of care. This can also be a great financial burden. Low cost In-Home and Respite care would greatly ease the burden.

In the case of Respite care, programs may be made possible by the federal (AOA) funding of demonstration grants. The need for low cost Respite care is overwelming. The type of constant caregiving necessary leaves little opportunity for

necessities such as the freedom to shop for groceries much less the time a caregiver needs away from their charge to promote their personal emotional well being. Had the option for respite been there for my family, I firmly believe, that my mother's (primary caregiver) physical health would not have suffered as it did. She was purely exhausted.

The care of the A.D. patieht is so all consuming that the caregiver inadvertently finds themselves divorced from their friends, careers, personal goals and in some instances family members who do not understand or cannot accept the stress. The caregiver's life is no longer their own but is governed by the needs of their charge. Respite care affords them their freedom. I cannot stress strongly enough the physical and emotional benefits of respite care.

The more physically and emotionally sound the caregiver, the longer the patient can be managed at home. At-Home care is much less costly, over the long term, than that in a nursing home.

In most cases, when the patient can no longer be cared for at home nursing homes are utilized. Over a five year period of nursing home care it is not unlikely for a family to spend $100,000.00. Many must reduce themselves to the poverty level before any assistance is available. It is imperative that the costs of specialized care needed for A.D. patients and home care costs are dealt with in congress. Families must be given the opportunity to care for their loved one and remain financially independent. Financial assistance in the care of a dementia patient if far preferable to public support of not only the patient but their entire family due to the need to exhaust their resources before being eligable for assistance. With an estimated four million dementia patients the financial implications are devestating.

Respite care alone will not ease the burden. It will take awareness. The public and Health Care Professionals alike need to be educated in the facts about the disease. It will take a committment to emotional support of the families as has been made possible by ADRDA Family Support Groups. It will take hope.

Hope will not find a cure. This can only be accomplished by a committment to research. Quality research, laboratory, clinical and social must be funded if we have any hope of controlling the devastating effects this disease could reap on society.

In conclusion the Comprehensive Alzheimer's Assistance, Research and Education Act of 1985 (CARE), H.R. 2280 provides the means to fight A.D. and its' far reaching effects. I most respectfully urge you as members of the Select Committee on Aging to encourage its' passage.

Thank You.

Clare Brown Lyle
1406 E. Maple
Mt. Pleasant, Michigan 48858
April 7, 1986

I am a board member of the Mid-Michigan Chapter of ADRDA and editor of its newsletter. However, I am speaking on behalf of myself.

I married Robert Lyle on Valentine's Day 1976. It was a second marriage for both of us. He was 62 and I was 55. We had five grown children between us.

Bob was the head of the accounting department of the Regional Center for Developmental Disabilities. He had eleven accountants working under him. I was the Extension Home Economist for Isabella County employed by the Cooperative Extension Service, Michigan State University.

Bob owned a modest home in Mt. Pleasant. I had a cottage on Lake Charlevoix. We had no debts. We each had new cars and money in the bank. We were two people in the prime of our lives who thought we had the world by the tail!

Six weeks later, Bob went into Central Michigan Community Hospital for two minor surgeries. He was given a general anesthetic. That night he had a severe drug reaction. (Many Alzheimer's victims report symptoms starting or being accelerated following general anesthetic.) He came back about 80%.

One of the first skills to go in Alzheimer's Disease is mathematics. One of the first symptoms noted is the patient's inability to manage their check book. Bob was typical in that respect. But Bob was an accountant. In six months he was in trouble at work. He retired (before he was fired) December 31, 1976.

Of course at this point, we had never heard of Alzheimer's Disease. Bob knew there was something wrong with him. We continually went from one doctor to the next specialist. He was diagnosed as early aging, premature senility, etc. Nothing helped.

The first year after his retirement wasn't so bad, looking back on it. I could cover for him socially. He did most of the house cleaning and yard work. He was a dapper dresser and was very fastidious about himself. He played golf. He attended conferences and workshops with me. He loved to travel. But he was loosing his speech. I thought perhaps he had had a stroke, so he attended the aphasia clinic at Central Michigan University. It was terrible to watch a grown man fill out papers: "The man that brings the mail is the _____". If he knew the answer, he couldn't spell it.

The second year we cleaned the house and took care of the lawn together. He said his arm hurt so he couldn't play golf. I would lay out his clothes for h ɜ to put on. When he attended conferences with me, he stayed in the room and I made a bee line for it at coffee breaks and lunch. He wanted to travel but became disoriented. We flew home after three days of a two week trip to Florida. Our conversations were based on the game of twenty questions. "Are you thinking about _____".

The third year I took care of the house and hired a man to do the yard work. I had to dress and bathe Bob. He wanted to go, go, go, all the daylight hours. In summer I was exhausted. In winter he was in bed by six p.m. I worked in the morning and whenever possible took him with me in the afternoon. I attended no conferences. There was no adult day care center then. When I had an out-of-town meeting, I paid a man $10.00 per hour to drive Bob around, take him to lunch, etc. Bob would be furious when I got home. All of my office work I did at home in the middle of the night as he slept. Bless my boss!

The fourth year was a nightmare. Bob continually thought he was ill. The doctors continually said they could do nothing. Bob couldn't be still. He was constantly dissatisfied. He no longer watched TV. He took his clothes off faster than I could dress him. He was afraid of his bath. He wanted to go but often became disoriented before you could get to the next town. He lost his temper and shook the lamps and the furniture. He forgot to use the bathroom and became incontinent with urine. He didn't recognize his own son. I retired early thinking that I could continue to care for him. Six months later, when he became bowel incontinent, I put him in the Medical Care Facility.

Bob was hospitalized before I ever heard of Alzheimer's Disease. Thank goodness I did then as I had to become his legal guardian. His daughter had fought this and his hospitalization every step of the way. When she found it was a disease with a name and that I was not just saying her father was crazy, it helped to reconcile her.

Also when I found the Alzheimer's Disease and Related Disorders support groups, it was wonderful. I had spent five years thinking I was the only one in the world going through such an ordeal. And here was a room full of people that were doing the same thing!

Institutionalizing Bob was good for me physically and emotionally, but it was devastating financially. I thought Medicare would cover the first three months expenses. But immediately he was classified as "custodial" so Medicare paid nothing. Then I had taken out a special insurance policy on Bob that was to cover nursing home care for six months. But they rejected the bills on the grounds that the facility where Bob was, accepted Medicare payments.

With an average monthly payment to the Medical Care Facility of $2250.00, nine months later, we were BROKE. I was frantic!

I could not get Medicaid help because our combined retirement income was too high. Yet by the time I made his payment to the facility, I had about a hundred dollars a month to live on.

My lawyer said the only solution was a divorce. That way Bob could receive Medicaid and I could retain my own retirement check to live on. I got the divorce. It was a legal piece of paper that gave Bob the care he needed. However, I continued to do his laundry and went to the facility twice a day to feed him for another fourteen months until he passed away.

After his death, I found that the divorce was a two edged sword. Because of it, the will was invalid. The insurance could not be paid to me. I only owned half of the house. I had signed for Bob's funeral expenses. It took over a year to straighten out that mess with his daughter. And because we were only married 7½ years, I can not collect his Social Security.

There are several needs for Alzheimer's Disease victims and their families. The first is a need for more research. As the median age of U.S. citizens increase, this is going to become a greater problem. And what of the next generation? Bob's children are scared this too may happen to them.

There also needs to be more adult day care facilities so that the partially disabled can be cared for during the day allowing the spouse time to work or to get away from it for a few hours. There should be para-professionally trained people to work with Alzheimer victims in their homes so they do not have to be hospitalized as quickly.

And last but not least, one should not have to be impoverished before you can receive Medicaid for long term care patients so that the spouse remaining can also live in dignity in their old age.

Statement for Field Hearing on Alzheimer's Disease. 4/11/86

Roger M. Morrell, M.D.,Ph.D.

I am Dr. Roger M. Morrell. I reside at 27754 Rackham Drive,Lathrup Village,Michigan(48076).Myopinions represent 11 years of experience as a Chief of Neurology Service at 2 V.A.Medical Centers,as a Professor of Neurology at Wayne State University, as past Chair of the Medical Advisory Board ,Detroit ADRDA,and as past organizer of a Kellogg Foundation sponsored international work group evaluating patterns of care in the dementias. My opinions are personal and professional, not official V.A.opinions.
The number of veterans over 65 and at risk for Alzheimer's will increase by the year 2000 from 10% to 30% of all veterans. The V.A.is responsible for treating and managing these patients .As one of the world's largest health systems, it has an opportunity to make significant contributions to clinical and scientific knowledge.There exist within the V.A.several centers devoted to clinical and scientific studies of the dementias.More are needed.
At this time, the V.A. does not meet minimal needs of patients with dementia or their families.First , there is no uniform protocol for diagnosis of dementia throughout the V.A.Those of us who met in Washington to develop field guidance material, were told in January of 1985 that no funds were available to distribute or promulgate our product. The guidance included a computer program for a data base to veterans representing ICD 9 dementia codes. Without a data base there can be no national clinical policy or program.There is no policy or support for the development of Geriatric Evaluation or Assessment Units.In some cases where these have been approved at the District level, priority conflicts have prevented their establishment.Second,V.A. facilities are generally inadequate to care for dementia patients.Third,eligibility and utilization criteria for dementias, including DRG weightings,are inadequate and vary regionally or by facility.There is no specific provision for extended or long-term care of dementia patients requiring institutionalization.Some demented veterans qualify for care while others equally entitled do not.Some families have to resume responsibility for a demented veteran after just 6 months of V.A. care.Fourth, the V.A. has virtually no daycare or respite facilities.Creative interaction with community agencies has generally not been undertaken.
Time does not permit listing other shortcomings.Solutions to the most serious deficiencies have been devised or suggested in parts of the V.A. system or in the private sector. What is now required is to establish national-level criteria and specifications in the critical areas,and to allocate resources sufficient not only to implement,but to sustain the V.A. mission in behalf of veterans with dementia. Thank you.

Dorothy A. Nini
3830 Vassar
Dearborn, Mich. 48124

April 7, 1986

Congressman Edward R. Roybal, Chairman
Select Committee on Aging
U.S. House of Representatives
Washington, D.C. 20515

I am writing to offer written testimony for the Field Hearings your committee is conducting in Detroit on April 11, 1986, on the comprehensive Alzheimer's Assistance, Research and Education Act of 1985 (CARE) H.R. 2280

My name is Dorothy Nini. I am the spouse of an Alzheimer's patient. I am a member of the Detroit Chapter of the Alzheimer's Disease & Related Disorders Association. I answer a hot-line and was an assistant Support Group leader. I've spoken in these capacities to perhaps 250 family members whose situations are similar to mine. However, my comments are on behalf of myself and family.

Sixteen years ago, at age 50, my husband was diagnosed as having pre-senial dementia. A common term used in the 1970's. The first five years he functioned fairly well with a lot of support from myself and children. It made me very protective of him and I watched him constantly. Then after five years, he had to leave workon a medical leave because he was becoming more confured and getting lost at work. In 1974 he had a complete neurological checkup, with EEG, PEG and CAT scan and it was determined that to the best of their knowledge, he had Alzheimer's Disease

Soon after that my husband had a seizure, he had been having problems walking. For a time he had problems eatting and his blood pressure had dropped quite low. The Doctor arranged to have a visiting nurse see him every week and an aide was to help me out two days a week After two weeks the aide stopped coming and several weeks after that the Visiting Nurse advised that because their funds had been cut back, she could no longer come, mainly because he was not termed a medical patient.after this his personality changed and he started to be agitated. He wandered, so we had to keep the doors locked. This caused him to be very agitated. Plus all this, he started pacing and staying up all night and day. He only rested on the couch or on the floor for 15 or 20 minutes twice a day. I was losing weight (30 lbs) due to the worry and anxiety and physical strain of caring for him. This was a most stressful time for all of us and his neurologist wanted me to place him in the State Hospital because he knew that nursing home placement was almost impossible because he was ambulatory. I realized that with him being non-verbal, confused and agitated, I would not trust his safety in the State Hospital. Even if I had been able to get a nursing home to accept him, the doctor said that being his health was good, he could survive 5 or more years. I'm sure that when we are advised to place an Alzheimer's patient in a nursing hom, that many doctors are not always aware that very few nursing homes will accept ambulatory Alzheimer's patients, and being termed not skilled care, many homes won't accept them. If they do accept them, some homes ask for 20 to 22,000 dollars in advance for the first year. Most families by this time have spent any savings paying for medical services or supplies. I know in 1984 I spent $4,500 in medical needs for my husband, and $4,700 in 1985. Not any part of it was covered by insurance or Medicare. I feel strongly that when a disease debilitates a person to the extent that Alzheimer's has affected my husband, it indeed should be recognized as a physical disease and covered under medical insurances and Medicare. My husbands condition is much like a stroke victim, yet stroke victims receive help and Alzheimer's patients don't.

I believe that if the status of the Alzheimer's patient was changed to a physical disease and families could avail themselves of a day or so of in home nursing services covered under insurances or medicare, patients could be kept at home longer. Bills that would allow us to deduct Home Care from our Federal Income Tax do not aid the families of the lower income families. These people are living on Social Security benefits and small pensions and their taxible income is so low they do not pay tax. Only those families who are in a higher tax bracket could take advantage of this deduction. As it is most families cannot afford the $7 to $8 an hour that is charged by most Home Health Services.

I would like to petition you to seek to change the status of the Alzheimer's victim so that they are recognized as having a physical disorder that would be covered by insurance coverage and Medicare. Secondly I would like you to consider having a pilot program for respite care, where we could take an Alzheimer's patient for a day or so a week, so that caregivers could regain their strength. I believe a program of this kind would enable families to keep the patient home longer. It certainly would do much to relieve the stress illnesses the caregivers suffer, such as high blood pressure, heart attacks, ulcers and stroke.

I feel these issues must be addressed because the financial drain on these families is causing them to become impoverished.

Thank You, Sincerely,

Dorothy Nini

Dorothy Nini

9557 Norborne
Redford, M. 48239
March 29, 1986

Congressman George W. Crockett,
House of Representatives
Washington, D.C. 20515

LC

Dear Sir;

I am writing to offer written testimony for the Field Hearings, your committee is conducting in Detroit, Mi. on April 11, 1986 on the Comprehensive Alzheimer's Assistance, Research and Education Act of 1985, H.R. 2280.

I am writing in regards "Horace N. Parker", who began four years ago to show signs, that he was being slowly transformed from a smart, alert, ambitious man to a person, who seemed to lack any desire to compete with life. Slowly, he began to lose control of his bladder and the will to be active.

I have taken him to all kinds of Drs. and he has had numerous tests, and it has been determined he is a victim of Alzheimer's, it has gotten to where I can not leave him alone, for even a few minutes, as he is liable to wander off. I have to hire someone to care for him, when I have to go to the store, get my hair done and ect. I have to set the alarm clock, to be sure he goes to the bathroom, (every two hours), by force.

The strain is getting to be too much, but what can I do? I am praying for the passage of Bill H.R. 2280, not only for myself, but for the thousands of others who are going through the same ordeal as I am.

Why! Try to allow a person to achieve a longer life, if something isn't done for those who are slowly slipping into a world of oblivion?

Thanking You, Sincerely,

Dorothy M. Parker

Prepared Statement of John E. Rex, Member of the Mid-Michigan Chapter and Midland, MI Support Group of ADRDA

My wife, Elaine, began having memory problems about eight years ago while we were living in Mansfield, OH and in the summer of 1978, underwent extensive neuropsychological testing including a CAT scan. Results of all tests were negative but none of the professionals involved suggested the possibility of Alzheimer's. In September, 1980, we moved to Midland and in the fall of 1982 I asked Dr. Dale Moliterno of Saginaw to try to determine Elaine's problem. By this time, I had heard of Alzheimer's and noticed many similarities between Elaine's condition and the standard Alzheimer symptoms. After 3 months of tests, in January, 1983, Dr. Moliterno announced that since the tests revealed no other cause of Elaine's problems, it was very likely Alzheimer's. During the summer of '83, we heard of a local Alzheimer's Support Group and attended our first meeting in August. If has been very helpful to share problems and discuss possible solutions with friends who were experiencing similar difficulties.

Elaine has experienced all of the usual Alzheimer "peculiar behavior" patterns such as wearing two similar articles of clothing, clothing put on backwards and buttoned crooked without realising it; wearing two different shoes; becoming extremely defensive and touchy and not being able to handle the slightest criticism or suggestion of alternate behavior; lack of patience with and understanding of young grandchildren; feeling that she knows everyone she sees in public places and greeting and hugging women (fortunately!) who are not acquainted with her; losing the ability to read, play the piano, cards, etc. Although my own opinion is that Elaine has not changed very much in the past three years, my children, who see her infrequently, tell me they feel she is continuing to slip. I admit to "being so deep in the forest, I can't see the trees." since except for being gone for 5 hours in the mornings, I am with her constantly and am her sole care-giver.

In approximately two months, because of job requirements, I have to go back on an 8-hour day on my job at SVSC and will have to provide some additional care for Elaine. A day-care center would be the ideal option but none exists in Midland. I heard at our last Support Group meeting a week ago that there are plans to open one here in several months. The only other option I know of is to try to find some woman who could act as a companion to Elaine while I'm gone. Incidentally, I am 66 and Elaine will be 66 in May.

I'm feel that I don't need to expatiate on the standard peculiarities and problems of Alzheimer's which I've learned from various professionals during the past three years. Such experts will supposedly be testifying directly to your Committee. However I strongly urge the members of this Committee to take the lead in passing The Comprehensive Alzheimer's Assistance, Research and Education Act of 1985.

APR 7

1617 Hayes St.
Marne, Mi. 49435
April 2, 1986

Congressman Edward R. Roybal, Chairman
Select Committee on Aging
U.S. House of Representatives
Washington, D.C. 20515

Dear Sir:

I am writing to offer written testimony for the Field Hearings your Committee is conducting in Detroit, April 11, 1986 on the Comprehensive Alzheimer's Assistance, Research, and Education Act of 1985 (care), HR2280.

I am a member of ADRDA in Grand Rapids, Mi. The comments I am about to make are on behalf of myself and my family.

In April of 1980 my husband, at the age of 57, and after some months of testing, was diagnosed as having Alzheimer's. Looking back I believe this was coming on him about 3 years previous to the diagnose. I took care of him nearly five years and fifteen months ago put him in a nursing home as it was beginning to take a toll on my health. Caring for an Alzheimer's patient truly makes for a 36 hour day. The care is constant but that is not the worst part, it is watching someone you love slowly regress until he no longer knows you, his children, or anything around him. The complete hopeless feeling one has is beyoud description. Now that I am alone and have time to think, even greater problems come to mind. We have seven sons and four daughters. What does the future hold for them? Until research comes up with a cause and cure I will never know a moments peace.

As if this were not enough, now comes the financial problems. At the end of 1980 my husband went on SSI. This did not cover our bills and we were then using some of our savings. In the following four years our cost of living was going up and it took more and more of our savings. On Dec. 1, 1984 he went into the nursing home. In 1985 the cost of his illness was very near $20,000. Then there was my living expenses. I see more and more younger people (in their early 50's) diagnosed with Alzheimers and this is even more devastating as they have to leave jobs, sell their businesses, still have children at home, etc. My husband owned an Insurance Agency, Sporting Goods Store, and Service Station, which have all been sold nearly ten years ago. I now know he was feeling unable to cope with the businesses, also back then inflation hadn't struck so at the prices the business was sold for would be triple today. I am sixty one years old and my future scares me. I pray I will never become a financial burden to my children. Everyday I think, if only he would die, and he is the one person I love the most. What an agony to live with. And they call these the golden years.

Sincerely,

Frieda Schneider

CC:
Nancy Opacki, Pres. of Grand Rapids ADRDA
Guy VanderJagt
Carl Levin, Senator
Donald Riegle, Jr., Senator

Alzheimer's Disease
and Related Disorders Association, Inc.
9370 East Rosebush Road • Mt. Pleasant, Michigan 48858

Mid-Michigan Chapter (517) 465-6602

4-5-86

Mary Ruth Seman
2243 Gaylord
Saginaw, Mi 48602

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Shirley Schafer
Helen Walton
Clare Brown Lyle
Jill Keelan
Chrystelle Walling
Terry Zajac

To whom it may concern:

I am a member of above Alzheimer's Chapter. Also support c/ leader in Saginaw and on the Mid-Michigan Chapter Board.

My husband has alzheimers and has been placed in a home for over five years now. He is only sixty-three (63) years of age. The following comments are my own:

The point I want to make is that even though I pay partial payments to Michigan Veterans Facility, Grand Rapids - I have paid over $29,000 in this time and my savings have been depleted.

Having been a care giver I know the need for adult day care centers and help for basic care. Keeping a loved one home is a tremendous physical, mental, emotional & financial drain.

Respite care is another need that has to be addressed now.

I urge you to bring this before the House Select Committee on Aging on Care Bills.

Sincerely
Mary Ruth Seman

April 7, 1986

Congressman Edward R. Roybal, Chairman
Select Committee on Aging
U.S. House of Representatives
Washington, D.C. 20515

Dear Congressman Roybal:

This letter provides written testimony for the Field Hearings your committee is conducting in Detroit on April 11, 1986 on the Comprehensive Alzheimer's Assistance, Research and Education Act of 1985 (CARE), H.R. 2280.

I serve as a family counselor and as a member of the Patient Care Committee for the ADRDA-Detroit Area Chapter. I am also a nurse educator and researcher. In these roles, I provide workshops and classes for practicing nurses and nursing students and conduct research, focusing on providing and generating information relevant to care of persons afflicted with Alzheimer's Disease (AD) or related disorders, and care of their families.

Family members do a remarkable job in providing care for and coping with the progressive changes in the persons afflicted with A.D. and in the life of the family. However, in most instances, the burdens of care, usually delegated to one family member, become too great, and family caregivers burn out, totally exhausted, often in deteriorating health themselves, and fraught with financial concerns.

The need for more available and affordable long term care provisions as evident. In particular, there is the need for a variety of supportive services deliverable to the home and in respite centers. Family members who seek counseling invariably will mention some of their expenses. They report paying a minimum of $7.00 per hour for an aide hired from a home health care egency. Whether working, or retired, this cost becomes prohibitive for a five day week. Adult day care services cost somewhat less, but patients resist this service in earlier stages of the disorder, and those in more advanced stages often have trouble adjusting to the unfamiliar day care environment, or if incontinent, cannot be easily readied for day care in the morning. Transportation to day care also has been cited as a problem.

Family members eventually become totally exhausted and may experience depression from the continual vigilance and care required by the restless patient, who has disturbed sleep pattern, and often wanders day and night. Research is needed to identify the measuras that can be used to help families plan ahead, and to determine the services most appropriate for patients with A.D. and their families. From clinical observtations, the incongruence between their present situation, and what families had envisioned for their mature years is great. Research and services are certainly needed to find ways that will enable families to cope and continue in their caregiving roles as long as is possible. The effectiveness of institutional services for those afflicted with AD and their families also nees exploration.

Sincerely, Dorothy E. Booth

Dorothy E. Booth, Ph.D., R.N., Asst. Professor of Nursing
Wayne State University, Detroit, Michigan 48202

Saginaw, Mich.
April 9, 1986

Committee on Aging
U. S. House of Representatives

Gentlemen:

My husband has had Alzheimers for at least six years. Our only daughter lives in Chicago so all care falls on me. He is up every night, all night long and cannot sleep in the daytime. Neither will he allow me to rest during the day. My health is deteriorating and I don't know how much longer I can carry on alone.

It would help so much if there was respite care that was funded. Also legislation to cover day care, medicaid, and a Home Health Care insurance under Medicare. This would be a tremendous help and would also save the Government in the long run.

This terrible disease is a complete drain, both emotionally and financially. Please pass legislation to help both the victims and families of Alzheimers disease and related disorders. I am in favor of Bill HR 2280, now before Congress.

Sincerely,
Mrs. Bernice Crampton
2426 Whitemore Place
Saginaw, Mich. 48602

March 20, 1986

To Whom IT May Concern:

I am writing to you regarding my Father who is a victim of Alzheimers disease.

No one can even imagine what Alzheimers can do to a family until they experience it themselves and I wouldn't wish it on anyone.

My father was a senior accountant at a General Motors Plant here in Saginaw, Michigan and now doesn't even know what the difference is between a penny and a dollar, or for that matter, he doesn't even know what money is anymore.

He knows none of his old friends except one that keeps in close contact and took him bowling until my dad didn't know how to do that anymore, and sometimes I am sure that he isn't sure who I am.

He doesn't eat hardly at all anymore, stays up all night and paces the floor, gets angry with my mother when she tries to get him to come to bed and has even gotten violent with her during those early morning hours after she has been up with him all night.

My father goes outside at 3 in the morning to shovel the snow, he no longer knows that he should go to a bathroom to urinate, so he just goes in his pants. He won't take his Blood pressure medication or any other medication that he needs to maintain his health and he just spits it out or clamps his mouth shut or puts it in the glass of water and watches it dissolve. Needless to say, his blood pressure is now always high.

My father can't talk anymore--other than a few words a week, if we are lucky, then those words are mixed up and sometimes we can't understand what he wants us to know.

My mother has heart trouble and can't take care of him anymore, as she can't get any sleep, and he has urinated on all the furniture in the house, and their bed many times and refuses to change his clothes, so we can not get a diaper on him. We have recently put my father into a Nursing HOme nearby, and went through the VA system to get him admitted into this home. Because my mother can't afford to have my father close by our home, (it would take every penny that she gets a month) he will have to go to a VA Nursing Home, and the closest one is 3 or 4 hours from our home, although we are now applying for admission to this home, we aren't sure how long it will take to get him in, or if he can get in, and how much they will expect my mother to pay each month.

There is no help for these victims of this awful disease, and I truly believe that the families suffer as much, if not more than the patients do themselves. It breaks my heart to see my Dad cry and cry and not know why or what I can do to help him feel better, and even if I could understand him, what hope could I give him ?????

Patty Close
12701 Frost
Hemlock, Michigan 48626

ROY W HAGGBERG
128 CUTTLE RD #E46
MARYSVILLE MI 48040

APR 15

Marysville, Mi. 48040
April 5, 1986

Congressman Edward R. Roybal Chairman
Select Committee on Aging
U.S. House of Representatives
Wash. D.C.

Dear Congressman Roybal

I am writing to give you first hand testimony to your Committee being conducted in Detroit, Mi. April 11, 1986 on Bill H.R. 3280 (CARE)

My concern is to my wife, 78 who is a victim of Alzheimers and parkinsons diseases and also to others who have the affliction.

We have been married 56 years. I am 80 years old, retired pharmacist and have been associated with the medical profession and health care all of my life. We all know what senility is, growing old and forgetting at times. However dementia and its related diseases, Alzheimers and Parkinsons, has come upon our older citizens quietly the last five years or so. so as now it has become a national problem, with no known cause or cure.

Researchers have been doing a great job with the funds available from Alzheimer's Disease and Related Disorders Assoc; private funds, and foundation grants and our government help. I hope that your Committee recommends increasing the governments appropriations a great deal.

The home care that I gave my wife lasted until last Oct. 1985 when she started or refused to open her mouth, then other body functions stopped also, I had to put her in the hospital. Tube feeding thru her nose, catherization and suctioning out her throat continued after leaving the hospital which was an eight day stay. A skilled nursing home was in order as there was no waywe could take care of her.

This program for nursing skilled care, doctors fee and medication I estimate will amount to $20,000.00 a year and could run more.

My recommendations to your Committee is that the government allocate more money for research and that a program such as a Fedral (Medicare) insurance program starting at age 50 to cover nursing home care, becomes effective at age 70.

I hope that your Committee will back this bill or act (CARE) to the limit so that others will eventually be freed from Alzheimers Disease.

Sincerely

Roy W Haggberg

To House Select Committee on Aging

I am a Board member of Mid-Mich. ADRDA Chapter and also an active in the Saginaw Support group, an affiliate of Mid-Mich. Chapter.

My husband was a victim of Alzheimers Disease and I was the sole caregiver for 13 yrs. He spent the last 4 years of his life in a nursing home in Saginaw and at the Mich. Veterans Facility in Grand Rapids (the last 2 years)

1) I am in favor of legislation for Day Care Centers, both for the Victim, and as relief for the Care giver.

2) Also, money is needed for further research

3) Alzheimers should be covered in a Nursing Home or other Care Facilities. If my husband hadn't been a veteran and a recipient of their care, I would be on Welfare today.

4) Also, Home Health Care for Alzheimers patients would be a cost saving procedure as many patients could remain at home if the care giver could have help in bathing, dressing, feeding etc.

We all know Health Care today, - in a nursing Home or Health Care at Home - is astronomical so I feel legislation is needed to help with this cost. The average income family cannot afford to pay for this help.

I hope S 1935 — "Alzheimers assistance Act of 1985" submitted by Senator Metzenbaum will be approved by Congress.

Respectfully submitted,

Jane K. Hillman
2147 Clover Lane
Saginaw, Mi 48602.

March 21, 1986

To Whom It May Concern:

I have a husband with Alzheimers and feel that I need to tell you that something must be done to help this people and their familes with this dread disease.

I have been married to this man for almost 50 years now and he certainly is no longer the man I once knew. Everyone changes over a period of 50 years, but not in this way.

He won't communicate with me anymore, days go by without a word, and this man who has always been a quiet man, with a very even temper, and very loving, is now becoming a man that doesn't even know how to give a hug anymore, and has pushed me across the room a number of times when I've tried to get him to come to bed after he has paced the floor until 3 AM. He acts some times as if he doesn't know me, and often as if he hates me. My life has been dedicated to him more and more, and there isn't much time left for me at all, because he has to be bathed, shaved, told to eat, which he won't do anymore, watched every minute of the day and night, 24 hours a day sometimes if he doesn't sleep and then he has to be dressed because he doesn't know if his pants go on his arms or his head or where they go.

He has lost control of his bladder and has wet on every thing in our house, and since he will not change his clothes with a physical fight, I cannot even get him to put on a diaper.

Recently, I have seen him cry out of frustration and paranoia, and it just about broke my heart because there is nothing I can do to help make things better for him or for me.

My oldest daughter lives close by, and is worried about myself and her father all the time, she calls me every morning and each night, to make sure that I am alright mentally and physically and to see if there is anything that can be done.

This disease is causing tremendous stress for our family all the way around, and since there is no help available for the people or the families of Alzheimers victims there seems to be no solution in sight to ease all the stress and heartache that this brings.

Recently we took my husband to the VA hospital in our town, as I find that I can no longer take care of him in our home and we were told that they were sorry but he could not be admitted because he had a disease that was not treatable. It would be better if he had cancer or some other disease because then they could treat him and take him into their system, but with Alzheimers, there is nothing they can do for it, so you are just left out in the cold with absolutely no help available.

Something HAS to be done for all the suffering people and their families with this problem, there is help for heart patients, cancer patients, stroke victims, etc, WHY not for Alzheimers victims ???????

Minnie Kipp
3333 Osler
Saginaw, Michigan 48602

Elizabeth G. Murray
40848 Newporte Drive
Plymouth, Mich.
48170 .

April 5, 1986

Congressman Edward R. Roybal, Chairman
Select Committee on Aging
U. S. House of Representatives
Washington, D. C. 20515

Gentlemen:

I am writing to offer written testimony for the Field Hearings your committee is conducting in Detroit on April 11, 1986 on the Comprehensive Alzheimer's Assistance, Research and Education Act of 1985, H.R. 2280.

I am a member of ADRDA-Detroit Area Chapter and active in a support group meeting in Plymouth. These comments are on behalf of myself and my family.

My husband is now in a nursing home, Westland Convalescent Home, Westland, Michigan. He has been there since November 1985 when it was impossible for me to take care of him at home. He is 79 and I am 77, he is a large strong man and became quite violent, I even had to call police at one time to help me out. For about a year this was coming on, that is lose of memory and disorientated, but able to function at home with my help. He is now incontinent, and is living in a world of 40 or more years ago. I go to see him every day, and the family that are nearby go every week, but the bad part is the cost.

I am paying $70.00 per day for his care plus the cost of medication that is given him. We are not rich, but have saved for our old age, both working into our 70's, and with Blue Cross, Medicare and small savings we could have made it fine. Now with the cost of $25,000.00 per year going to the home, and my living here in a condo in Plymouth, it won't be too long before we both will have to go on welfare. Of course Social Security helps a lot, but it does seem that something could be done to help out people like me.

Sincerely,

Elizabeth G. Murray